

# SPONDYLITISPLUS

winter 2007



**WHY  
THIS COVER  
IMAGE IS  
ONE OF  
THE MOST  
IMPORTANT  
PHOTOS  
YOU WILL SEE  
THIS YEAR.**

SEE PAGE 4

## SPONDYLITIS ASSOCIATION OF AMERICA

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

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## SPONDYLITISPLUS

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## UPFRONT



ON SEPTEMBER 29TH, SAA STAFF TRAVELED TO NEW York to present our first Patient Educational Seminar in the area. We were pleased to receive such a positive response from the local spondyloarthritis community. The room was packed with 150 attendees. Our presenters, Dr. Asim Khan, Dr. Lehman and Dr. Cohen provided the audience with wide-ranging and comprehensive presentations on various aspects of the disease.

Dr. Khan shared his own story about living with AS since childhood. In addition, he talked about the important breakthroughs in the medical management of spondyloarthritis that have come about in recent years. The breakout sessions, where patients, families and friends shared information and support, were scheduled to end by 3:30 pm. At 5:00 pm, we still had a room of 35 attendees tossing a wide variety of questions at Dr. Khan, who answered every one as he shared his perspective and experience with the disease.

We are very fortunate to have such loyal Medical Advisory Board members as Dr. Khan, who contribute so much to our Patient Educational Forums and program services. In addition, we are greatly appreciative of the other physicians who give talks at these programs on our behalf.

Maintaining excellence in patient educational programs has traditionally been a cornerstone of SAA's mission. This past year, and looking forward, SAA provides programs and services to more people than ever before. We plan to visit New York on a regular basis and look forward to meeting other SAA members during our upcoming visits to Seattle and Atlanta.

As we near the year-end, we all celebrate the wonderful reports from the TASC Genetic Study, which you can read about on pages four and five of this issue of Spondylitis Plus.

Katherine Culpepper  
EXECUTIVE DIRECTOR



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COVER: New genes that have now been implicated in AS.

### Clothing Issues

We have been members of SAA for about a year and look forward to each issue. My husband was mentioned in your spring 2007 magazine on "Driving Safely With AS". Our problem is that his back is broad and hunched, neck is 22", and sleeve is 33-34". We are having a difficult time finding dress shirts for him. Do know of any sources for buying clothing for people with AS? We have had suits, blazers and shirts custom-made, but his posture changes within a year or so and there is only enough excess material for one or two alterations. We are retired and it is impractical to custom- make his clothes.

We would appreciate any suggestions that you might have.

DIANA SAWYER, via E-mail

**Editor's note:** *If anyone has suggestions with regard to this question, please send them along to [chris.miller@spondylitis.org](mailto:chris.miller@spondylitis.org)*

### No Problem with Blood Donations

I have been diagnosed with AS and have been told by the blood donor services that as result, I cannot donate blood. Since I was curious to explore this further, I recently asked Dr. Michael Ward at the National Institutes of Health about this issue. Dr. Ward was very surprised that I had been turned down as a blood donor, and said that there is no reason why I can't also be an organ donor, which I have interest in eventually becoming—as stated on my driver's license.

I thought that others with AS would be interested in hearing my story. Thank you.

DIANE SKWISZ, Leesburg, VA

### New Blood Markers in AS

Thank you to you, and the Spondylitis Association of America for all that you do! Being part of this organization really helps me to feel less alone.

I noticed in the most recent edition of Spondylitis Plus (summer 2007) that there is a new blood marker called MMP3. Is this test being used in real life or is it still just in research? Thank you.

JANET MARSHALL, Cleveland, OH

**Dr. Walter Maksymowych's response:** *This biomarker is still being used only in research. However, the results look very promising and if a second study can repeat these findings then we will have a very useful test for predicting disease severity and progression. In AS patients who are already showing some signs of damage in the spine, an elevated MMP3 is highly predictive of further damage.*

### Is Surgery for Me?

I have had ankylosing spondylitis for over 20 years and am just now finding I'm looking down a lot. Is there an operation available to "straighten" me up a little. The Health Science Centre in Winnipeg, Manitoba was using me as a case study because I have more move-

ment, virtually no pain and am quite strong as opposed to many others. Your valued opinion would be appreciated.

DOUG ROBINSON, via E-mail

**Editor's note:** *Please see the CME story in this issue with regard to your question.*

### Unusual Treatment

Why am I reading your website and not finding anything at all about treating A.S. with low-dose naltrexone?

SLIM RANGLES, Albuquerque, NM

**Response from the SAA Medical and Scientific Advisory Board:** *It has not been shown to advantage patients with chronic inflammatory diseases, spondylitis in particular. We are aware of no systematic studies underway and would not support such a trial.*

## LETTERS TO THE EDITOR

*Dear Readers:* We want to hear from you, whether it be informative, uplifting, or a gripe you need to express. Include your full name, address and daytime phone number.

We reserve the right to edit for space and clarity.

*Please send letters to:*  
Laurie.Savage@spondylitis.org  
Letters to Editor/SAA  
P.O. Box 5872, Sherman Oaks, CA 91413



## THE TASC GENETIC STUDY UNCOVERS TWO NEW GENES IMPLICATED IN ANKYLOSING SPONDYLITIS

Laurie M. Savage | *Editor*

The good news is in. We are delighted to tell you that due, in large part, to your continued commitment to AS genetic research since 1996, a critical milestone has been achieved with the discovery of two new genes implicated in AS. The new genes have been identified as ARTS1\* and IL-23R\*. This new finding means that researchers now have uncovered roughly 70% of the genetic contribution toward susceptibility toward AS.

### What does this mean for patients?

This new information resulting from the work coming out of the TASC genetic study, headed by Drs. John D. Reveille and Matthew Brown, provides two more critical pieces of the puzzle with regard to unraveling the mystery of how AS develops. Further, the discovery of IL-23R could very likely lead to new biological medicines in the treatment of AS with new clinical trials beginning as early as within two years. The reason for this likelihood is that IL-23R has already been implicated in Crohn's Disease and as a result research has already begun to develop a class of drugs specific to this gene target. What is more, researchers are suggesting that eventually these findings very likely will lead to a faster diagnosis for people who show early symptoms of AS.

### Who conducted the study?

Work done in part by the Australo-Anglo-American Spondylitis Consortium (TASC), which includes the SAA, led to the discovery of the two genes. The findings, which will be announced in the November issue of *Nature, Genetics*, resulted from the largest and most comprehensive genome-wide association scan ever conducted to date. Several other unrelated diseases were included in this scan. These included breast cancer and multiple sclerosis, but according to the AS researchers, it is encouraging to note that most significant findings were in AS.

## How did genetic studies start?

In 1944, three researchers at Rockefeller University published a paper that laid a foundation for the modern revolution called molecular biology. By discovering that DNA is the material that is involved in transmitting genetic information, the good and the not-so-good, from one generation to the next, Avery, MacLeod and McCarty paved the way for the work later picked up by Crick, Watson and Wilkins in the early 1950s, which eventually led to a Nobel Prize award for elucidating DNA's structure.

What many people do not realize is that the original pivotal work actually was driven by the quest to understand a specific disease; pneumonia. During that epoch—in the early decades of the 20th century, pneumonia was the leading cause of death in America. It was responsible for the premature death of more people than cancer or heart disease.

Without the investigation of how certain types of pneumonia “transformed” into others, the discovery that DNA carried genetic information would most likely not have been uncovered as early as it was.

Fast forward to the 1970s. Humans have roughly between 20,000 and 25,000 genes, but according to researchers, fewer than a dozen most likely play any significant role in AS. The first of these genes, HLA-B27, was discovered in the 1970s. At that time this was a spectacular and important discovery to aid diagnosis in some patients, and also led to a better understanding of the worldwide distribution of the disease in different populations, since it was recognized early on that the rate of HLA-B27 in population largely determined the likely prevalence of AS.

It is thought that HLA-B27 accounts for approximately 40 percent of the overall cause of AS, and now with this new discovery, according to Drs. Reveille and Brown, together with B27, the identified genetic susceptibility toward AS now stands at roughly 70 percent of the overall cause.

## How is AS triggered in a person?

Many AS researchers think that AS occurs because people carrying particular combinations of genes are exposed to some common environmental trigger, most likely some bacteria that we carry in the gut. This suggests that it is likely that nearly everyone is exposed to the trigger, but only those with particular combinations of genes develop the disease.

## What is DNA?

DNA, or deoxyribonucleic acid, is the hereditary material in humans and most other organisms. Most DNA is located in the cell nucleus (where it is called nuclear DNA), but a small amount of DNA can also be found in the mitochondria, where it is called mitochondrial DNA or mtDNA.

The information in DNA is stored as a code made up of four chemical bases: adenine (A), guanine (G), cytosine (C), and thymine (T). Human DNA consists of about 3 billion bases, and more than 99 percent of those bases are the same in all people. The order, or sequence, of these bases determines the information available for building and maintaining an organism, similar to the way in which letters of the alphabet appear in a certain order to form words and sentences.

DNA bases pair up with each other, A with T and C with G, to form units called base pairs. Each base is also attached to a sugar molecule and a phosphate molecule. Together, a base, sugar, and phosphate are called a nucleotide. Nucleotides are arranged in two long strands that form a spiral called a double helix. The structure of the double helix is somewhat like a ladder, with the base pairs forming the ladder's rungs and the sugar and phosphate molecules forming the vertical sidepieces of the ladder.

An important property of DNA is that it can replicate, or make copies of itself. Each strand of DNA in the double helix can serve as a pattern for duplicating the sequence of bases. This is critical when cells divide because each new cell needs to have an exact copy of the DNA present in the old cell.

## What does the future hold?

Research typically advances in micro-steps that are barely perceptible even within the scientific community itself. However, this discovery is much more significant with far reaching potential. Indeed, the researchers tell us that the identification of these new genes will become part of the AS permanent record upon which new and important future advances will be made.

In an interview with Spondylitis Plus from Brisbane, Australia, Dr. Matthew Brown stated that the scan that identified these two genes looked at around 15% of the genetic diversity between individuals, and that going forward the Australo-Anglo-American Spondyloarthritis Consortium study (TASC) will survey 80-85% of that diversity, and so is likely to find still more genes. He concluded, “We can expect really major advances then over the next 5 years in AS research on the back of these genetic studies - these are very exciting times indeed.”

The SAA acknowledges with deep gratitude the work of Drs. Reveille and Brown and the TASC team, in addition to the researchers at the Wellcome Trust in Oxford, UK, who have made this discovery possible.

*Reference: NIH.gov*

*Glossary: The unabbreviated name for the IL23R gene is “interleukin 23 receptor”*

*The unabbreviated name for the ARTS1 gene is “type 1 tumor necrosis factor receptor shedding aminopeptidase regulator”*

# ACROSS THE MILES...

Melissa Velez | *Contributor*

## Spokane Wellness Fair

**CALIFORNIA** In September, the Spondylitis Educational Support Group in Spokane, Washington, presented their first informational booth at the Senior Health and Wellness Fair on the Spokane Community College Campus. The one-day event provided an opportunity for the group to raise awareness and disseminate information about spondylitis to the thousands of people who attended the event, which featured guest speakers, musical presentations, informational booths, art exhibits and food.

Joan Polzin, the group's leader, said she "felt energized and thrilled to reach so many people in such a short time and to hear heartwarming personal stories". Two members of the support group assisted Joan, as they talked to people interested in learning more about spondylitis.

Those who had been diagnosed with spondylitis were eager to receive more information about the group and to be notified of upcoming meetings. Some people shared that they knew someone with the disease and would share SAA's educational material with them. A few folks shared frustrations of having spondylitis symptoms and no diagnosis; they were looking forward to presenting the information provided at the booth to their general practitioners.

Overall, the Spokane, WA Educational Support Group felt that their time at the health fair was a resounding success and they look forward to participating in future events to continue to raise awareness in their community.

### SUPPORT FROM SAA

As part of our commitment to fostering education, raising awareness and promoting earlier diagnosis of spondylitis, SAA is providing tabletop displays and informational brochures to Educational Support Groups who participate in their local community health fairs.



## New Support Group Leader

**VIRGINIA** Sam Brumberg is a new Spondylitis Educational Support Group Leader for Richmond, where he is an attorney-at-law. A native of Richmond, Sam is an associate in the Government Relations and Regulated Industries group at LeClairRyan, Virginia's fifth-largest law firm. His practice consists of providing advice and counsel to electric utility, cooperative, and telecommunications industry clients.

During law school Sam was diagnosed with Crohn's Disease and ankylosing spondylitis of enteropathic etiology (arthritis of the spine associated with inflammatory bowel disease). He received his undergraduate degree in Political Science summa cum laude from the University of Richmond. Sam is married and lives in the historic Fan District of downtown Richmond. Also, he is fluent in Spanish and French.

## Group Meeting Highlights

**CALIFORNIA** A recent San Diego Educational Support Group Meeting featured Dr. Dean Nakadate, a podiatrist, who spoke about foot problems associated with spondyloarthritis and treatment options. In addition, Dr. Nakadate discussed common footwear problems. For example, he stressed that dress shoes should flex near the toe not in the middle where arch support is critical and major wear on the shoe's heel can really alter one's gait and lead to foot issues. Other topics such as orthotics and last resort surgical procedures were also reviewed.

**ARIZONA** At the September Phoenix group meeting, attendees were treated to a presentation by Kelly Knapp of Desert Song Yoga. Ms. Knapp demonstrated various massage techniques for parts of the body that trouble individuals with spondylitis. She also taught attendees some basic yoga techniques.

**IDAHO** The Boise group met in September to learn more about Exercise for People with Spondylitis from Susan Gordon, lead physical therapist for arthritis at St. Luke's Idaho Elks Rehabilitation Hospital. Susan clearly described why exercise is important and gave group members examples of appropriate exercises. You can learn more about this group by visiting their website at <http://www.sageecosci.com/spondylitis.html>.

## 8th Ankylosing Spondylitis International Federation Meeting in Prague

Laurie M. Savage | *Editor*

DURING THE FIRST WEEK OF SEPTEMBER, THIRTY EIGHT AS delegates, including SAA's Laurie Savage, representing eighteen countries, got together to share information and expertise with regard to the AS patient experience worldwide. The Ankylosing Society International Federation (ASIF) meeting was held in the small mountain town of Jachymov, which is located about 130 miles from Prague in the Czech Republic .

Jachymov is renowned for its spa facilities that specialize in the treatment of rheumatic diseases. The treatments that are offered at the spa are centered around natural spring waters which contain the radioactive gas, radon. People with rheumatic diseases immerse in "radon baths" to which they attribute improved joint mobility and increased blood circulation. The twenty minute baths are administered at a temperature between 35-37 degrees C in order to achieve the desired therapeutic effect. The minimum number of immersions for maximum benefit per stay is twenty four. Approximately 2,000 AS patients visit the spa annually upon their rheumatologists' recommendation in order to benefit from this form of therapy.

ASIF was founded in 1988 to increase public awareness of ankylosing spondylitis and to share information about the disease worldwide. SAA is a member society of ASIF and was associated with its establishment; however, this is the first time that we have attended a Council Meeting. The meetings take place approximately every two years.

During the three day meeting, the delegates discussed the issues of late diagnosis and access to treatments. We learned from each other that some countries are facing more problems with regard to treatment than others—specifically, those associated with adequate access. We were told that AS patients in Belgium, Ireland, France and Denmark have good access to the biological treatments and that they are not experiencing major issues with regard to care. Akin to the US, the Czechs, the British and the Norwegians are facing significant problems, quite often due to the inconsistencies of the various program and payer models. In Belgium, AS is divided into a special category of diseases called e-pathologies, which entitles people with AS to specific discounted treatments such as physiotherapy.

One of the highlights of the meeting was the presentation of the ASAS/EULAR A.S. Treatment Recommendations. The study group that initiated this effort is comprised of international researchers in AS from France, Germany, Canada and others. The objective of the study, which is ongoing, is to develop evidence-based recommendations for the management of AS. Currently, there is a list of ten areas of recommendations. These include the exploration of the overall impact of the disease on a person and quality of life issues, consistent disease monitoring, treatment options, non-drug treatments such as exercise, pain control recommendations, specialized treatment and surgery. Each of these domains is being studied by the group in order to design a treatment paradigm for optimum health of the person with AS. We will make sure to keep you updated as the study advances.

### New Study In Search of Data

Would you like to help researchers find out about the impact of anti-rheumatic drugs on pregnancy?

Dr. Feldtkeller of the German society, requested our participation in an important study. If you would like to help, please download the research form from the SAA website, which you will find in the news section at [www.spondylitis.org](http://www.spondylitis.org)

Once you have completed the form, please mail to SAA so that we can send completed questionnaires along to Dr. Monika Ostensen, affiliated with the Bern Hospital, Switzerland, who is conducting the study. We will tell you about the results of the study once the data has been analyzed and published. The spectrum of medications against

rheumatic diseases like ankylosing spondylitis has been dramatically increased in recent years. An essential innovation in this respect are the drugs classified as "biologics," which inhibit the pro-inflammatory substance "TNF-alpha" in the human body. TNF-alpha blocking drugs have effectively decreased the disease activity in many patients with ankylosing spondylitis. Besides their positive effect, there is also great uncertainty with respect to the question: How safe is it if a patient wants to become father or mother during the treatment with one of the new drugs? Which drug taken before or even during pregnancy may have a

negative effect on the offspring? Very little is known about this because new drugs are never tested on pregnant woman. Only tests with pregnant animals are available. They have never indicated a harmful influence on the offspring; the uncertainty remains however, in relation to effects on humans.

To close this gap of knowledge, a research project was initiated in collaboration with ASIF. With the help of a questionnaire, information will be captured on pregnancies which ended later than January 1st 2000 where a patient with ankylosing spondylitis was either the father or the mother of the infant—whether or not the parent was on any type of anti-rheumatic medication. The researchers are seeking to compare pregnancies with and without drug therapy.

# A YEAR OF ACHIEVEMENT

Diann Peterson | Contributor

DID YOU KNOW THAT THERE ARE UP TO ONE AND A HALF MILLION PEOPLE in the United States who have ankylosing spondylitis? And when you include the other forms of spondyloarthritis, the number climbs to well over three million. If you consider that each spondylitis patient has a minimum of five friends or family members who are affected by their diagnosis, that's — conservatively — over 15 million people living with the effects of the disease.

And the Spondylitis Association is the only organization in the country to put their needs first. By producing publications and materials, presenting patient educational seminars throughout the country, providing access to support groups, online message boards, a comprehensive website and leading the push to increase funding for spondylitis research, SAA is committed to serving the needs of the spondylitis community, whatever they may be. And we're able to do it because of your support.

This is an exciting time in the spondylitis world. As you read on pages 4 and 5, the TASC genetic study, which SAA is a part of, has just announced a groundbreaking discovery that will change the face of this disease. Since 1996, SAA has been the principal champion in the campaign to accelerate and increase funding for spondylitis research.

Just as your past support has been instrumental in making SAA the leading voice of the spondylitis community, your continued support is vital to ensuring that SAA remains a driving force in educating the medical community, supporting patients and their families and advancing research that will someday lead to a cure. It is for that reason that I hope you will give as generously as possible this holiday season.

With all of us working together, we can beat this disease.

## THIRD TIME'S A CHARM!

CHARITY NAVIGATOR, AMERICA'S premier independent charity evaluator, has awarded SAA our *THIRD* consecutive



4-star rating, for our ability to efficiently allocate and grow our finances. Only 9% of the charities rated have received three consec-

utive 4-star evaluations, indicating that SAA outperforms the vast majority of charities in America in its efforts to operate in the most fiscally responsible way possible.

This "exceptional" rating from Charity Navigator differentiates SAA from its peers and demonstrates to our members, donors and friends that the organization is worthy of the trust they have shown us.

## GOING, GOING, GONE!

LAST YEAR, SAA'S ANNUAL EBAY auction brought in more money than ever before. Collector's items, theatre tickets, weekend stays, and even airline tickets came in from supporters far and wide. **We received over 100 items** and auctioned them off on eBay, making the 4th Annual Stand Tall Auction a rousing success.

And now, we're gearing up to do it again. Next Spring, we will be holding the Fifth Annual Stand Tall Auction to raise funds for the programs and services that improve the lives of those living with spondylitis. All proceeds from the auction go directly to furthering SAA's mission to be a leader in the quest cure AS and related diseases and to empower those affected to live life to the fullest.

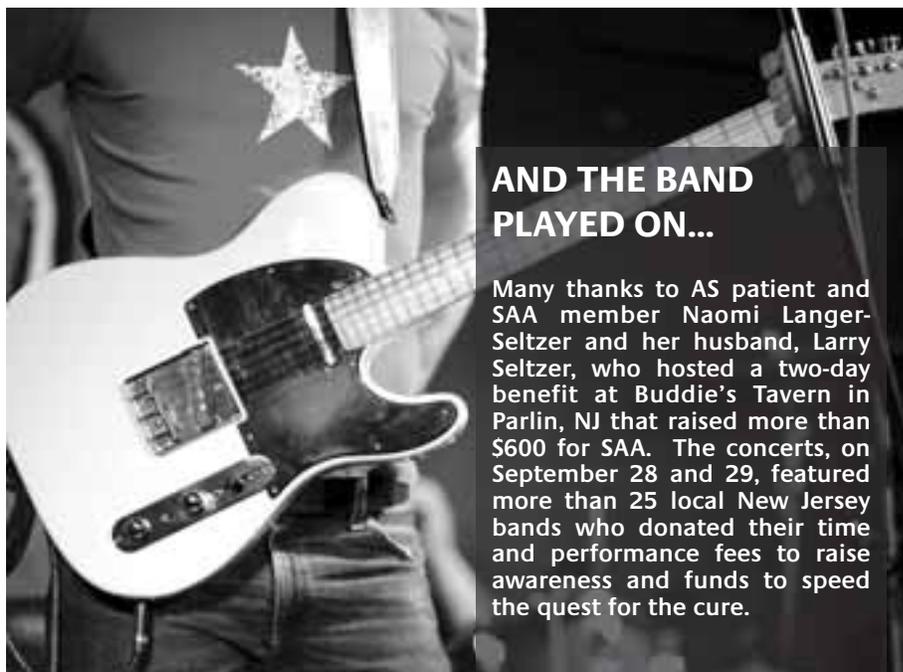
CONTINUES NEXT PAGE



We're looking to you to help donate or solicit items (with a value of \$50.00 or more) to be put up for auction. Supporters just like you made a valuable contribution to our auction last year by sending us auto-graphed memorabilia, hotel stays, restaurant certificates, fitness packages, signed books, jewelry, theatre and travel tickets, getaway packages and artwork.

And this year, we're asking again. If you would like to make a donation to our auction, please contact us today at [auction@spondylitis.org](mailto:auction@spondylitis.org).

Please include your name, phone number, what you're donating (and the monetary value, if you know it, with a minimum value of \$50.00), and a good time for us to reach you. If you have any questions, send us an email at [auction@spondylitis.org](mailto:auction@spondylitis.org). All donations are tax-deductible to the fullest extent of the law. We need your support! Our auction runs on the generosity of our members and friends.



## AND THE BAND PLAYED ON...

Many thanks to AS patient and SAA member Naomi Langer-Seltzer and her husband, Larry Seltzer, who hosted a two-day benefit at Buddie's Tavern in Parlin, NJ that raised more than \$600 for SAA. The concerts, on September 28 and 29, featured more than 25 local New Jersey bands who donated their time and performance fees to raise awareness and funds to speed the quest for the cure.

## eBay GIVING WORKS

A SPECIAL THANKS TO ALL THE MEMBERS WHO HAVE AUCTIONED ITEMS on eBay's Giving Works to benefit SAA. Not familiar with Giving Works? eBay Giving Works is the dedicated program for charity listings on eBay, enabling you to list items and donate part or all of the final sale price to your favorite nonprofit organization. It's a fun and easy way to support SAA.



## GROCERY SHOP FOR SAA

If you live in Southern California, you can earn money for SAA every time you swipe your Ralph's Club Card when buying groceries. It's easy to enroll online:

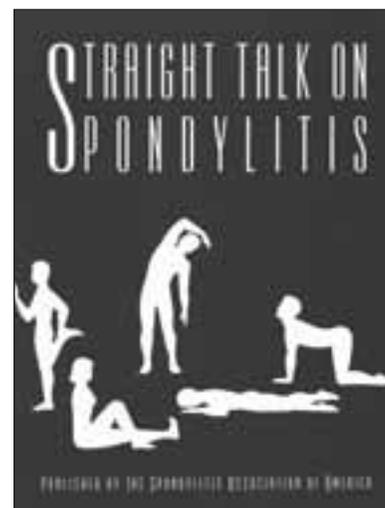
- Visit [www.Ralphs.com](http://www.Ralphs.com)
- Click on Community Contribution (lower left)
- Fill in SAA's NPO number — 84668
- Fill in your Ralph's card number
- Fill in your address and you're done!

If you typically use your phone number when checking out, call 800-660-9003 to get your club card number so that you can enroll. It's a win-win situation — you still get the benefit of lower grocery prices and SAA benefits as well! Not in Southern California? Let us know if a store in your area offers a similar program and we'll sign up.

## NO SMALL TALK

SAA'S LONGEST RUNNING SUPPORTERS, THE JB AND EMILY VAN NUYS Charities, have partially funded the revision of Straight Talk on Spondylitis. This groundbreaking, internationally recognized book was first published in 1985 as the first ever educational text written specifically for the spondylitis patient. SAA, in conjunction with our volunteer medical board, has updated and revised this important work to reflect the medical advances that have been made, many of which the SAA was instrumental in bringing about.

If you have an idea for a fundraiser, contact Diann Peterson at 818-981-1616, ext 226 or at [diann.peterson@spondylitis.org](mailto:diann.peterson@spondylitis.org). Can one volunteer make a difference? Absolutely!





## EXAMINING CORRECTIVE SURGERY

Over the years, SAA members with long-standing, severe disease have asked us about corrective surgical procedures. They have wanted to know where these procedures are performed, by whom, and the list of potential risk factors.

Laurie M. Savage | *Editor*

Typically, when we think about this type of surgical procedure, we are usually referring to the correction of the fixed forward stoop (kyphosis) that a small percentage of AS patients experience, usually after years of disease. Most people with AS will never need to consider this procedure as an option—especially since the advent of new drugs called biologics, which show much promise.

However, for those people who experience extreme kyphosis, daily life can be fraught with challenges that most of us cannot even imagine. Hence, we recognize the critical need for information regarding kyphosis corrective surgery.

Up until very recently, there have been very few surgeons in the US with adequate knowledge and experience with respect to this type surgery and as a result there were limited resources available to the patient seeking guidance in this area.

This situation is beginning to change. In March of this year, SAA collaborated with the Cedars-Sinai Institute for Spinal Disorders to bring about a day-long Continuing Medical Education Conference for rheumatologists, primary care and internal medicine physicians, orthopedic surgeons and neurosurgeons to educate and inform them about ankylosing spondylitis and corrective surgery for the AS patient.

**“Any AS patient with sudden onset of neck (back pain), regardless of how trivial, should be considered to have a fracture until proven otherwise.”**

– Dr. Brian Perri, OD, Associate Director

The goals of the conference included in-depth and high-level presentations by the experts to improve the attendees’ recognition of the types of spine deformity and

trauma seen in AS and what can be done to help. Among other things, attendees heard about the current medical management of AS, new instrumentation and surgical techniques in spinal surgery, and how to recognize and potentially improve the pre-operative and post-operative risk factors associated with AS.

The conference was unique--breaking new ground in AS education for doctors. It is the goal of Dr Patrick Johnson, Director, who hosted the conference, and his team at Cedars-Sinai Institute for Spinal Disorders, to become recognized as a center of excellence in surgical procedures for AS patients and others in need of a top-notch team of highly trained, talented and very caring group of spine surgeons.

The very comprehensive conference included eleven talks spanning the medical management of AS and early diagnosis issues to medical problems facing the AS patient undergoing surgery and spine trauma and the AS patient.

In these pages, we present some of the critical issues that were discussed during the conference. For more information, you will be able to view and hear all of the lectures from the conference in the Physicians' Section at [www.spondylitis.org](http://www.spondylitis.org) Please see the note at the end of this article for more information.

## Advances in Spinal Surgery

Dr. J. Patrick Johnson, Director of the Cedars-Sinai Institute for Spinal Disorders, and Dr Justin Paquette, Associate Director, Neurosurgery and Spinal Neurosurgery, discussed the advances in spinal surgery. These include:

- Microsurgical technique
- Improved understanding of spinal anatomy and biomechanics
- Operating microscopes
- Much improved lighting
- Enhanced instrumentation
- Minimally invasive techniques

- Increased strength and performance of the instrumentation

Dr. Paquette emphasized during his talk that advanced anesthesia and antiseptic techniques and patient monitoring have greatly improved during recent years. He concluded that advancement in spinal biologics now lead to better outcomes with the use of bone growth extenders, bone morphogenic proteins and injectable proteins and disc replacements.

Dr Lionel Hunt, Director, Spine Trauma, gave a talk that addressed the characteristics of spinal deformity in long-standing, severe AS. He told the attendees that the treatment greatly depends upon the main

cause of the problem whether it be related to the hips or to the different, specific areas of the spine. He surprised some of the attendees by saying that in some patients a total hip replacement is sometimes necessary prior to treatment of the spine.

## Posture Loss Assessment

- Examination seated, standing, lying down:

- If the upright posture loss is corrected from standing to the seated position – the hip joints are the cause

[CONTINUES NEXT PAGE](#)

**“In the case of spine fracture in the AS patient, plain x-rays are very often negative. Advanced imaging studies, using CT and MRI are very often necessary to identify the fracture.”**



■ If the upright posture loss is corrected from a seated position to a lying down position –thoracic and/or lumbar are the cause

■ If the posture loss is not corrected in the lying down position – then the cervicothoracic area is the main cause of the posture problem

## AS Patients + Surgery

Dr. Mariko Ishimori, who is on the Faculty and Assistant Professor of Medicine in the rheumatology department of Cedars-Sinai Medical Center in Los Angeles, presented the topic entitled, The Medical Programs Facing the Ankylosing Spondylitis Patient Undergoing Surgery.

During his talk, Dr. Ishimori emphasized the need for critical pre-operative considerations in AS patients with long-standing disease. These considerations include:

- Screening for the potential of cardiovascular involvement in AS patients, which based on the medical literature is more common than previously believed.

■ Risk factors for cardiac complications in AS:

- Patient's age
- Duration of disease
- HLA-B27 positivity

- Screening for pulmonary disease which can be a late, rare manifestation in 1-2% of people with AS:

■ Typically asymptomatic

■ Slow progression and often in both lungs



**Dr. Lionel Hunt surprised some by saying that a total hip replacement is sometimes necessary prior to treatment of the spine.**

- Recognition of the potential of reduced chest expansion and other airway issues:

■ Many people with AS have restriction in the movement of the chest due to extra bone formation

■ The kyphosis can sometimes lead to impaired lung function; specifically pulmonary drainage

■ Temporomandibular joint (TMJ) arthritis may also be seen in some people with AS

■ The TMJ may cause mouth opening problems that prevent the use of the traditional instruments requiring awake intubation under fiberoptic visualization

- Screening for unknown spine fracture of

the cervical spine using imaging technology and careful positioning during the imaging procedure to ensure that any unknown fracture not be inadvertently displaced.

- In rare cases of late, severe AS, during intubation and surgery, Dr. Ishimori explained the potential risk of causing displacement of the bones of the spine, subluxation, particularly those of the bones in the cervical spine (neck region), which can lead to spinal cord injury. He discussed the special handling techniques to avoid this problem.

- Finally, Dr. Ishimori offered a creative suggestion when working with an AS patient. He suggested that if a soft cervical collar is worn by an AS patient throughout the preoperative period it can serve as a visual reminder of the spinal disease.

Please know that the entire CME program has been converted for the online environment and will eventually be available to view in the Physicians' Section of [www.spondylitis.org](http://www.spondylitis.org) It is important to remember that the program was designed and developed for the practicing physician and that laypeople and patients may find the graphical images very disturbing to view.

## CORPORATE PARTNERSHIP PROGRAM

The Corporate Partnership Program provides a way for the Spondylitis Association's pharmaceutical partners to positively impact the spondylitis community by contributing funds to the organization's general operating budget. We would like to thank the following partners who played a vital role in helping to fund SAA's educational programs and services\* through their partnerships. Partnership levels range from \$20,000 to \$80,000.

### Premier Corporate Partners



### Associate Corporate Partner



### Supporting Corporate Partner



*\*The Spondylitis Association of America is solely responsible for the content of all educational programs and services.*

## Stay Informed With SAA Online - Spondylitis.org

*New features, weekly news and much more*

Christopher Joshua Miller | *Contributor*

SAA's website, [spondylitis.org](http://spondylitis.org), is an ever-evolving source of information for both members and non-members alike. With research continually generating new information, with upcoming seminars, support group meetings and personal stories being added, there is always a reason to check back to [spondylitis.org](http://spondylitis.org) regularly to see what's new.

Over the last year, for instance, we have added a number of features that you should find valuable and informative:

- A brand new *SAA Weekly News* section that is updated each week with research news, program announcements, hot forum topics and more: [www.spondylitis.org/press](http://www.spondylitis.org/press)

- New member area features including the new *eBook: Your Guide To Living With Ankylosing Spondylitis*, all seven of our brochures, and not to mention more personal stories from our members: [www.spondylitis.org/members](http://www.spondylitis.org/members)

- A *Questions & Answers Compilation* where doctors answer your questions on ankylosing spondylitis and related diseases: [www.spondylitis.org/about/experts.aspx](http://www.spondylitis.org/about/experts.aspx)

- In addition, a sleeker version of our safe, secure online store with new donation options and simplified interface is now online: [www.spondylitis.org/store](http://www.spondylitis.org/store)

And that is just the proverbial "tip of the iceberg" in regards to the most recent updates and new features on [spondylitis.org](http://spondylitis.org). We have new versions of our forums, are continually adding information on topics like fatigue, treatments, and medication, as well as comments and quotes from members on what it really feels like to be someone who has spondylitis.



### MONTHLY E-LETTER

Sign-up for our FREE email newsletter, the SAA UPDATE, and the first week of each month you will receive links to the latest news, research, upcoming events and more – all sent right to your inbox!

Just go sign-up at:  
[www.spondylitis.org/saa\\_update.aspx](http://www.spondylitis.org/saa_update.aspx)

### COMING SOON

Be on the lookout for a new support groups' section, a new online resource guide in the member area and even a brand new look with navigation that will allow you to get to the information you want even faster. So stop by [spondylitis.org](http://spondylitis.org) weekly for breaking news, to see if there is an upcoming support group meeting in your area, to check out upcoming seminars and events, or even to visit the SAA Forums for 24/7 online support with people from all over the world.

SAA is always there for you online at [spondylitis.org](http://spondylitis.org)

## Community Education & Support Meeting Facilitators

The people listed below are a vital part of our support system. They have volunteered to lead support groups across the US because they want to help. If you'd like to find out more about support groups and online meetings, pick up the phone or send an e-mail to: [melissa.velez@spondylitis.org](mailto:melissa.velez@spondylitis.org)

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Spokane, WA	Joan Polzin	<a href="mailto:joanp115@webband.com">joanp115@webband.com</a>	(509) 624-8214

- Teen Athletes with AS located in Orange County - contact [WalkerRSM@aol.com](mailto:WalkerRSM@aol.com) for more info.
- Support online from NY, NY with Michael T. Smith, [spenser23@aol.com](mailto:spenser23@aol.com).



## TOTALLY COOL!

Announcing a new website from SAA:  
S.W.I.F.T. (Spondylitis Web Info For Teens)  
<http://teens.spondylitis.org>

Are you a teen with AS and have a story to tell?

For more information contact  
[Chris.miller@spondylitis.org](mailto:Chris.miller@spondylitis.org)  
[Melissa.velez@spondylitis.org](mailto:Melissa.velez@spondylitis.org)

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The process is quick and easy, includes free pick-up or towing, and best of all the proceeds go to a cause near and dear to your heart— The Spondylitis Association of America. The vehicle doesn't even have to run for you to donate it. Consult with your tax advisor prior to donating a vehicle. Call Helene Hart at (800) 777-8189 X 229 for more information.



## Are you willing to help researchers find the genes involved in ankylosing spondylitis?

### How can I help?

If so, you may be interested in participating in our study. To participate you need to be at least 18 years of age, and to have been diagnosed with ankylosing spondylitis. The study is also enrolling non-affected spouses and friends.

### Who is conducting the study?

The study is sponsored by the National Institutes of Health. The researchers conducting the study are Principal Investigator, John D. Reveille, MD, University of Texas, Houston; and colleagues, Michael H. Weisman, MD, Cedars-Sinai Medical Center, Los Angeles

### How can I find out more?

Southern California: Felice Lin, (310) 423-2422, linf@csha.org  
Houston area: Laura Diekman, (713) 500-6852, laura.diekman@uth.tmc.edu

Spondylitis Association of America Toll Free 1-800-777-8189 x 224

## NEWS FLASH!

Remember to visit the SAA weekly news at:  
[www.spondylitis.org/press](http://www.spondylitis.org/press)

Each week we post the latest news in research, community, events and more. Updated each Monday evening, come visit us and stay informed!

## Let's Stay in Touch

If you've recently moved, changed phone numbers or switched to a new email address, help us stay in touch by letting us know how to reach you. Contact Helene Hart at [hhart@spondylitis.org](mailto:hhart@spondylitis.org) or at 800-777-8189, ext. 229.

*Your personal information is never sold, traded or shared with anyone.*

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24/7**

SAA members can now access exclusive content in the member area. Login with your email address and ZIP code at:

**[www.spondylitis.org](http://www.spondylitis.org)**



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