

SPONDYLITISPLUS

fall 2007



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DIFFERENCE

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INSURANCE
WATERS

SPONDYLITIS ASSOCIATION OF AMERICA

P.O. Box 5872
Sherman Oaks, CA 91413
Phone (818) 981-1616 or (800) 777-8189
Fax (818) 981-9826
e-mail: info@spondylitis.org
www.spondylitis.org

SAA MISSION

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

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SPONDYLITISPLUS

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UPFRONT



I AM PLEASED TO ANNOUNCE TWO RECENT ADDITIONS to the SAA Board of Directors. John Reveille, MD, and Karrie Shogren, PhD, have each been involved with SAA for a number of years and each brings considerable expertise and leadership skills to the organization.

Dr. Reveille has been involved with SAA for two decades, serving on the Medical & Scientific Advisory Board since 1991, authoring publications and participating in SAA's Patient Educational Seminars throughout the country. Dr. Reveille lives in Houston, where he is a Professor of Medicine and Director of the Division of Rheumatology and Clinical Immunogenetics at The University of Texas Medical School. In addition, Dr. Reveille serves as the Principal Investigator for the TASC Genetic Study (Triple "A" Spondylitis Consortium), which involves an international team of researchers in the U.K., Australia and the U.S.

Professor Karrie Shogren served as a leader of an SAA Support Group for four years while she lived in Lawrence, Kansas. At the University of Kansas, Karrie received numerous awards and honors during her doctoral work in Special Education, in addition to co-founding the University of Kansas Professionals for Disability. Moreover, Karrie worked on a number of committees focused on planning and program evaluation for the Greater Kansas City Chapter of the Arthritis Foundation, in addition to serving on the Arthritis Community Task Force of the Department of Health and Environment. Last year, Karrie relocated to Austin, Texas, where she is at the University of Texas at Austin, as Assistant Professor, Ph.D., Department of Special Education, Autism & Developmental Disabilities.

I am delighted to welcome both Dr. Reveille and Professor Shogren to the board and look forward to their expanded involvement with SAA.

Thank you to all the donors who responded to the Spring Appeal and/or participated in the SAA eBay Auction in May. Your continued support ensures our ability to provide a wide array of patient programs and fund continuing research projects.

Katherine Culpepper
EXECUTIVE DIRECTOR



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A clear view on driving

I enjoyed your article on driving safely (Spring, 2007) - accidents are certainly one of my worries! However, I was surprised that there was no mention about eliminating a car's blind spots by adjusting the mirrors. The trick is to minimize overlap with the side view and rear view mirrors. I have very limited neck mobility due to my AS, and this works great for me. One clear set of instructions is on the web site for Car Talk. Here's the URL: <http://cartalk.com/content/features/mirrors/>. I don't mean to say that specialty mirrors aren't useful, but this is worth trying.

There was mention of the importance of having your head close to the head rest to give more protection in the event of an accident. I find this is a great time to practice my chin tuck exercises. It's a stretch, but I try to keep the back of my head as close to the head rest as possible while (of course) looking straight ahead. Maybe it's wishful thinking, but I figure this might give me a better chance in the event of an accident. Now, if I could only remember to do my chin tucks the rest of the day...

JOHN ZENKER, Charlottesville, VA

No spuds, no pain

I was diagnosed with AS three years ago at the age of 22. I already have extremely calcified sacroiliac joints and am HLA-B27 positive. I have always been in a great deal of pain and had stiffness in my joints. Last year, a friend, who is a massage therapist, suggested that I try removing the nightshade family of

plants from my diet. These include potatoes, tomatoes, eggplant, sweet potatoes and some peppers. She told me that in some people these can cause joint sensitivity.

Anyway, I decided to give it a try since with the constant pain, I didn't seem to have much to lose by trying it for a while. After one month, I felt like a normal person and no longer like an old disabled person. I am now twenty five years old and have almost no joint pain. I do realize that one person's experience hardly builds a case to support a treatment regimen, but given my life-changing experience, I just thought that I should let you know, just in case someone else might experience the same relief that I have.

TSIPA SWAN, Via email

Tips when submitting a claim

With regard to your recent story entitled, The Money Puzzle, I have an opinion and personal experience that I would also like to share on this issue which is based on my years of experience as a benefits specialist and a patient.

I was very fortunate that it took less than 30 days to receive approval of my claims from both Social Security and my employer's disability company. There were most likely several important reasons for this prompt approval. I believe that the most critical one is that I submitted my forms and the doctor's forms at the same time. Both my forms and the doctor's form were complete along with clinical notes, radiology reports, lab reports,

medications and other related materials. Another most likely reason for the fast approval was that I was 59 years old at the time. Both Social Security and private disability companies are more inclined to approve disability claims faster if the claimant is "older" as they will have fewer years to pay benefits. Another contributing factor was that at the time of my filing, I had suffered with AS for 40 years, so I had lots of medical records showing decreased motion, advanced fusing, total hip replacement, and continued decrease in quality of life.

If you decide not to work with a specialized SSI attorney or patient advocate, but rather to file on your own behalf, my professional and personal suggestion would be to make sure that your forms and your doctor's forms are submitted together, and that your doctor's forms include back-up information (i.e., reports, clinic notes, etc.) to verify your inability to perform your job.

LYNDA E. SMITH, Lewisburg, PA

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

GENETICS AND ANKYLOSING SPONDYLITIS SUSCEPTIBILITY: THE NEXT STEP—THE TASC STUDY

By Dr. John D. Reveille



One of the indisputable facts about ankylosing spondylitis (AS) is that hereditary factors play a critical role in its cause. We have known for many years that AS and the related conditions associated with spondyloarthritis (such as psoriasis, iritis or uveitis, and inflammatory bowel disease) occur more frequently in family members of AS patients than in the general population. For nearly 35 years we have known that one hereditary factor, HLA-B27, is extremely important in susceptibility. The significance

of HLA-B27 became even clearer with the development of the HLA-B27 transgenic rat in 1990, a model that continues to teach us about the immunology of this disease.

Genetic investigations in the 1990s were focused on finding susceptibility genes in families for many diseases such as diabetes, rheumatoid arthritis and lupus using a technique known as genome-wide scanning with DNA markers called microsatellites, which allowed an examination of the human genome much like mile markers on a superhighway. Accordingly, in 1998 the Spondylitis Association of America collaborated with Dr. John Reveille at the University of Texas Health Science Center at Houston to launch the AS Family Genetic Project. SAA's efforts led to the National Institute of Arthritis, Musculoskeletal and Skin Disease (NIAMS/NIH) providing funding for Dr. Reveille and the SAA to establish the North American Spondylitis Consortium (NASC), a collaboration between ten academic medical centers in the US and Canada aimed at collecting family data and performing genetic analyses in the susceptibility to AS.

During the period that NASC was funded, between 1999 and 2004, data from nearly 400 AS-affected sibling pairs was collected. A genome-wide association study was completed and published that identified, in addition to the major histocompatibility complex on chromosome 6, several other genetic regions on other chromosomes, whose importance was magnified when the NASC data was pooled with the data from the British and French scans. In addition, several candidate genes were examined, some not confirmed and some, such as interleukin 1, a cytokine that is very important in inflammation whose gene is found on chromosome 2, that have now been recognized as adding to HLA-B27 in the risk for AS.

Recent advances in genetic analysis have led to new approaches in unlocking the genome. Today, computerized chip technology has

Recent advances in genetic analysis have led to new approaches in unlocking the genome. Today, computerized chip technology has allowed dissection of the human genome not just with 400 markers, the limit of the previous microsatellite technology, but to up to 1,000,000 markers. The challenges presented by this approach include its expense (more than could normally be covered by an NIH grant) and that large numbers of patients (in the thousands) and healthy controls are required.

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Recognizing that this new technology was necessary to achieve the cure, we have entered into a partnership that involves not only US investigators and the SAA, but also parallel efforts in the UK, with whom we have already established a working relationship in pooling data from our previous genome-wide scans. This new team transcends NASC and is called TASC (the Triple A--Australian-Anglo-American--Spondylitis Consortium), which has been funded for five years by NIAMS.

TASC is headed by myself and co-Principal Investigator, Dr. Matthew A. Brown, who has joint appointments at the Wellcome Trust at the University of Oxford and at the University of Queensland in Brisbane, Australia. The TASC Project consists of four projects, aided by two core facilities.

The first project will use SNP chip technology to study 317,000 single nucleotide polymorphisms (SNPs) scattered throughout the genome in 1,000 UK and 1,000 US AS patients compared to 3,000 UK controls (provided at no cost by the Wellcome Trust Case Control Consortium) and 1,000 US controls (provided by Dr. Peter Gregersen of North Shore Hospital, one of the external advisors to TASC). This scan is already nearly half done, and will be finished by early 2008. Genes found to be associated with AS in both the UK and US groups will be further studied in additional cohorts of 1,000 new UK AS patients and

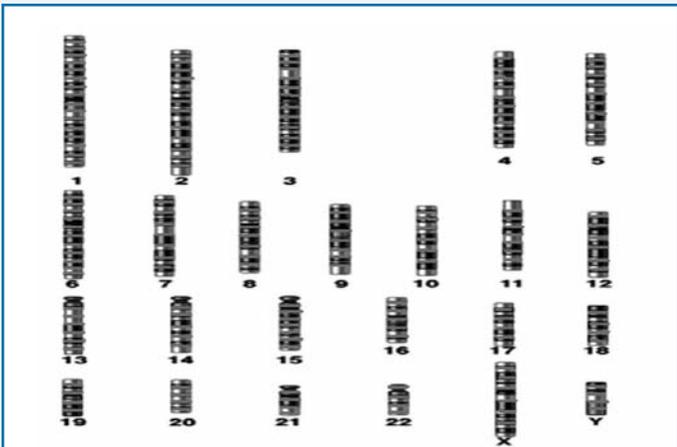


FIGURE 1. An Example of the Manner in Which the Human Chromosomes (Genome) are Studied by Microsatellite Markers, Spaced at Regular Intervals Throughout the Genome Much Like Mile Markers on a Highway.

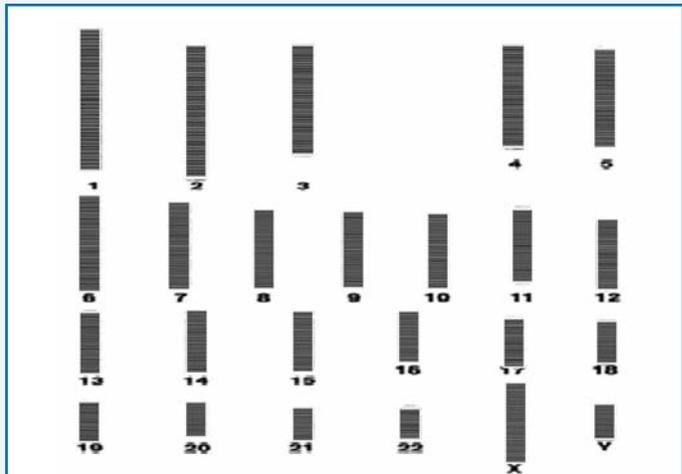


FIGURE 2. A Visualization of the Much Denser Coverage of the Human Chromosomes (Genome) Provided by SNP Chip Genomewide Association Studies, Where SNPs Spaced at Regular Intervals Throughout the Genome are Examined.

500 US AS patients (coming largely from the membership of SAA) who are being presently being enrolled. Project 1 will include Drs. Reveille and Brown, as well as Dr. Paul Wordsworth, representing the Wellcome Trust Case Control Consortium from Oxford, England.

Project 2 focuses on using the data from the SNP chips in Project 1 to examine genes impacting disease severity. Genes in a living person work in conjunction with and are affected by a variety of non-genetic factors, such as socioeconomic status, ethnicity, education, psychological and behavioral factors, personal habits such as smoking, drinking and exercise, and other medical problems such as obesity, high blood pressure and diabetes. Consequently, this project will examine both genetic factors and non-genetic factors and their impact on prognosis in AS, including radiographic severity, functioning, disability, and quality of life. This project will be overseen by Dr. Michael Weisman at Cedars-Sinai Medical Center, in conjunction with Drs. Reveille, Michael Ward from the NIAMS/NIH Clinical Center, Millicent Stone from the Bath Royal United Hospital, Dr. Perry Nicassio, a noted psychologist from UCLA, and Thomas Learch, a bone and joint radiologist from Cedars-Sinai. Overall, 900 patients from Cedars-Sinai, UT-Houston, the NIH and UCSF will be enrolled.

Project 3 focuses on the immediate family members of patients with AS and the spectrum of related diseases that occurs in them, including inflammatory back pain, arthritis, uveitis, inflammatory bowel disease and psoriasis, as well as defining the genes associated therewith. It is headed by Drs. Reveille, Weisman and Tammy Martin at Oregon Health and Science University.

Genetic and environmental factors don't work in a vacuum, but in

networks together. Previous statistical methods proved inadequate to account for these interactions, requiring the development of new statistical paradigms, which is the focus of project 4. The project will be headed by Dr. Momiao Xiong at the University of Texas at Houston, a statistical geneticist, in conjunction with Dr. Lon Cardon of Oxford University.

Overseeing TASC will be an Administrative Core, headed by Drs. Reveille and Brown, in conjunction with Laura Diekman, the TASC Program Manager, Omolade Ogun, SAA Research Coordinator and Laurie Savage, SAA Associate Executive Director, who will oversee the SAA's nationwide recruitment of patients and families. The genetic analyses and blood samples will be handled by the Laboratory Core, overseen by Drs. Xiaodong Zhou at UT-H and Dr. Matthew Brown at the University of Queensland.

TASC has already yielded some exciting new discoveries, which will be detailed in a subsequent issue of Spondylitis Plus, and the genome-wide association study will be complete by early next year. The genes we are identifying will need further characterization and validation in additional patients, and the SAA continues to play a critical role in this effort. SAA's partnerships with members of the research community have had success that few other advocacy organizations can claim. The TASC study will forever be a testimony to the generosity, hard work and commitment not only of the researchers, but also the SAA membership, who remain the community to which we are responsible. You have been critical contributors to this research, and we hope you will continue to partner with us in the very exciting work that lies ahead as the genetic basis of AS susceptibility and the determinants of prognosis and outcome are dissected.

Questions

Answers

QUESTION

Why is there still such a long delay between the onset of symptoms and the confirmed diagnosis of the disease?

ANSWER

There are many reasons for this. First, the diagnosis is not easy to make early on in the disease and consequently, is often misclassified. Second, the disease presents in many different forms. For instance, sometimes, a person will experience joint pain but no back pain. At other times, an individual may experience just neck pain at the beginning, or even iritis with no back pain. Then again, some people, in more rare situations, will have no pain at all, but rather x-ray evidence of sacroiliitis.

One study, in conjunction with the SAA, is seeking to develop a screening tool to help with earlier diagnosis.

QUESTION

What is the typical pattern of symptoms once the disease is established?

ANSWER

The disease is really very mixed. In the early stages there may be long periods of time



where it is quiet. Onset may take place in the twenties, but even during the teenage years, an individual may already have had something going on that just “didn’t feel right.” At the beginning you can’t see AS on normal x-rays, though researchers do not believe that a pre-spondylitic phase exists for many people.

QUESTION

What is the prevalence of AS and related diseases in the U.S.?

ANSWER

No one really knows. A study was done in 1998 to look at the numbers in the U.S., but the study was flawed since the number of cases that were accounted for was based on x-rays of sacroiliac joints. Since plain x-rays do not show inflammation, but rather take pictures of the bones, you have to have a certain amount of damage to the bone for it to show up. But you can have lots of damage in the joint prior to damage showing up on the plain x-ray. MRI is showing a potential in early diagnosis, but researchers are still trying to develop a validated scoring system that can be used for this purpose.

QUESTION

How much of the risk of getting AS is related to genetics?

ANSWER

Genetics play a very big part in disease susceptibility in AS. When compared to other genetic diseases, the concordance of AS in identical twins is 63% compared to 15% in rheumatoid arthritis and 25% in lupus. Hence, the importance of our conducting genetic research in AS.

QUESTION

Why do the different biologics (TNF-a blockers) work for some people for a period of time and then become less effective?

ANSWER

There is a great deal of variability with regard to how an individual responds to medication. This includes the newer biologics as well as the traditional anti-inflammatory drugs (NSAIDs). Sometimes, the mechanism of action of a given medication will be efficacious or not depending upon the stage of a person's disease. Sometimes it has to do with the individual's make-up. In the case of the biologics, each one has a different mechanism and therefore, one might work better than another at different stages of a person's disease. No one size fits all. The good news is that when one stops working or has a reduced efficacy, one of the others, when prescribed, may be an effective replacement.

QUESTION

What are the main side-effects associated with biologics in AS?

ANSWER

To date, most of the side-effects associated with the biologics have been observed in studies in rheumatoid arthritis (RA). Very few side-effects have been documented in AS. RA is a disease that already predisposes to certain risks such as getting more infections and being more susceptible to certain types of malignancies, like lymphomas. These are the concerns also associated with the biologics. What has been suggested is that if you already have a greater tendency toward a malignancy, then these drugs may tend to bring out the malignancy at a greater frequency. However, the data does not necessarily support this thesis. When we look at the data, with regard to this issue, they do not show an increased frequency of these malignancies in people who are receiving biological therapy.

The one known side-effect in AS patients is the risk that some of the biologics can unmask tuberculosis (TB) in a patient with latent TB. If your doctor discovers that you have latent TB, biologics can still be prescribed along with anti-TB medication. There are no drugs free of side effects. The issues must be weighed carefully.

QUESTION

I was treated for more than 29 years for back pain. After all of those years, it was a

diagnosis of iritis that clued the general practitioner (GP) that I might have AS. Family practitioners were not able to diagnose me. They thought that I had RA. Why can't we create a greater awareness of the disease among GPs?

ANSWER

The diagnosis of AS has always been a big problem, though patients are telling us that there have been improvements in recent years. In part, this is due to the work of SAA, the wide distribution of its educational brochures and the widespread accessibility of www.spondylitis.org. One reason we are developing the screening tool is so that patients can become their own advocates. With the screening tool, you can take the test and if you come up with a 30% likelihood of having the disease, you can go to the doctor and request a B27 test. It will work just like Direct-To-Consumer Advertising, which is very successful at educating the public with regard to drugs available to treat certain diseases.

QUESTION

What can you tell us with regard to prescribing the biologics to someone who suffers from chronic infections? Is it safe?

ANSWER

We are very cautious about prescribing biologics to patients with a history of chronic infections. However, infections can be treated. Hence, we must weigh the decision. The biggest concern here is associated with potentially triggering those infections and/or making them worse.

QUESTION

What about biologics in pregnancy?

ANSWER

They appear to be safe, but there is no data to support that theory. There does not seem to be a higher risk during pregnancy either to the baby or to the mother. Typically we recommend that pregnant women go off the drug and use either no medication at all or other, safer drugs during the nine-month period of gestation.

QUESTION

When should we have our children tested for the marker?

ANSWER

Unless it is for research purposes, doctors do not see any reason to test a child if there are no symptoms. That would potentially just create extra worry, concern and anxiety unnecessarily. If and when symptoms are present, that is when one should be concerned.

QUESTION

Can you tell us anything about the other common symptoms such as fatigue, weight loss and low-grade fever.

ANSWER

Some people with AS experience a systemic or whole body disease. These symptoms sometimes mask the disease in young people. Through our genetic studies, we are trying to identify which genes are associated with the more systemic disease which affects the whole body, and which genes are associated with the type of disease that affects only the peripheral joints and spine. That will be able to help us improve both diagnostically and therapeutically. We are at the forefront of being able to address these issues and thus anticipate better treatments in the future once those genes are identified.

QUESTION

Could disease be triggered by trauma?

ANSWER

We do not know whether trauma is a trigger, but we do know that trauma can be very important once a person has the disease. Proper studies have to be done in order to find out if trauma actually is a trigger.

WE ACKNOWLEDGE with great appreciation Drs. Weisman and Siddique and Professor D. Garnett for volunteering their time to share their expertise at the SAA Spondyloarthritis Educational Seminar in Los Angeles.

The program was funded by a generous educational grant from Amgen and Wyeth Pharmaceuticals

Dear Readers, we welcome your questions with regard to AS or the Related Diseases for inclusion in this section of Spondylitis Plus. We do ask that questions be of potential universal interest to others. Responses by the experts to selected questions will be published in this journal and on our Web site, www.spondylitis.org. We look forward to hearing from you.

Email questions to: Laurie.savage@spondylitis.org

SAA's Spring Appeal Sets Record!

2007 marked only the second time we've asked for unrestricted donations in the Spring. Our first such effort, in 2005, resulted in 361 donations and total revenue of \$17,600. To date, this year's Spring Appeal has more than doubled those results, raising over \$42,000 from 515 gifts!

Our sincere thanks to those who sent in a contribution and helped make the appeal a success.

But Records are Made to Be Broken...

SAA's broad menu of programs and services cannot be supported solely through membership fees. In fact, membership fees account for only 9% of SAA's yearly operating budget. 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 yet sent a gift, 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 -- our 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.

Plus, you can rest assured that your money is being used responsibly. Charity Navigator, America's number one independent charity evaluator, has awarded SAA two consecutive 4-star ratings for our ability to efficiently manage our finances. Fewer than 12% of the charities rated have achieved this feat, indicating that SAA outperforms the vast majority of charities in the country in terms of fiscal responsibility.

Anniversary Couple Makes SAA the Beneficiary of Gifts

Longtime SAA members Earl and Susan Broidy are celebrating their 40th wedding anniversary and showing their support for the organization at the same time. In lieu of gifts, they've requested that friends and family make a tribute donation to SAA in their



Earl and Susan Broidy celebrate 40 years of marriage with gifts to SAA.

honor. Earl, a former SAA board member, said, "I joined the board of the Spondylitis Association in its early years because I saw a need and thought that this was an organization that could help make a difference in people's lives." Earl and Susan are still helping to make that difference. Congratulations on 40 years of matrimony!

Fourth Annual SAA eBay Auction Reaches New Heights

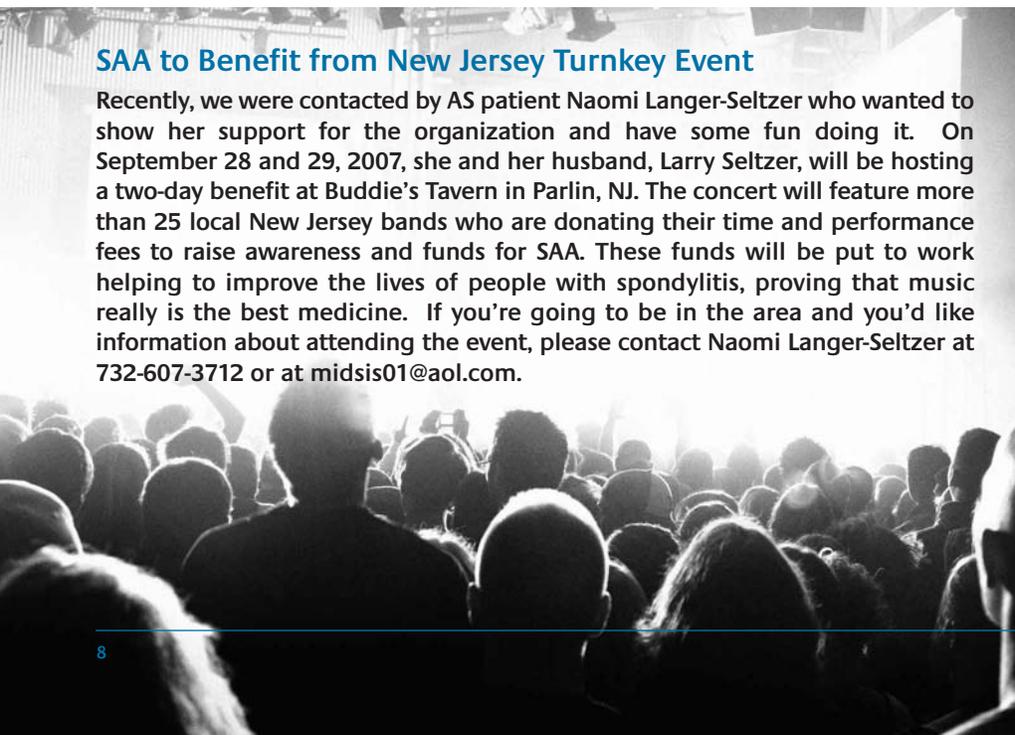
SAA's online auction began as a small, volunteer-fueled event three years ago. Four events later, the auction has proven to be a solid money-maker that also serves to get the word out about AS and SAA to a global audience. As the word has spread, more and more people are logging in to participate in this popular fundraiser. SAA members have also been instrumental in procuring and donating items to be auctioned. This year's event more than doubled our first-time earnings. With almost 100 auction items on the block, SAA members and friends bid enthusiastically during the one-week event. This next year, we really want to "kick it up a notch" by forming a National Online Auction Committee to grow this grass-roots event into the super-fundraiser we know it can be.

Amgen and Wyeth Partner with SAA to Fund Seminar

Amgen and Wyeth have been major supporters of the Spondylitis Association's Patient Educational Seminars throughout the United States. We are excited to announce that Amgen and Wyeth have provided \$14,000 in

SAA to Benefit from New Jersey Turnkey Event

Recently, we were contacted by AS patient Naomi Langer-Seltzer who wanted to show her support for the organization and have some fun doing it. On September 28 and 29, 2007, she and her husband, Larry Seltzer, will be hosting a two-day benefit at Buddie's Tavern in Parlin, NJ. The concert will feature more than 25 local New Jersey bands who are donating their time and performance fees to raise awareness and funds for SAA. These funds will be put to work helping to improve the lives of people with spondylitis, proving that music really is the best medicine. If you're going to be in the area and you'd like information about attending the event, please contact Naomi Langer-Seltzer at 732-607-3712 or at midsis01@aol.com.



funding for SAA's program activities which has enabled us to schedule a Patient Educational Seminar early next year in Atlanta, GA.

For many years, SAA has been the only organization to hold large-scale educational meetings around the country to address the number one need identified by patients -- access to accurate information about current thinking in disease management and treatment options. The seminars put patients directly in touch with experts in spondylitis so they can be properly informed of their current choices of therapies, treatments and coping skills to better manage the disease. Thanks to the support of Amgen and Wyeth, SAA will be able to bring Atlanta area patients and family members together with the leading experts in the field of spondylitis.

Easy Ways That You Can Get Involved with SAA

Volunteering is an American tradition that has made an immeasurable contribution to communities, organizations, and individuals throughout the country. Today's volunteers are active, dynamic, creative individuals who possess the skills, desire, patience, and time to accomplish a wide variety of tasks. There are several ways that you can get involved and help raise the funds that SAA needs to remain in the forefront of spondylitis research, treatment and advocacy:

SOLICIT auction donation items for SAA. This is the single, best way to make an impact in helping raise funds and awareness for SAA. During the coming year, SAA hopes to grow its annual online auction into a powerhouse event that really packs a



Ask your favorite neighborhood retailer to donate a portion of sales to SAA.



Put a donation to SAA on your wedding registry.

punch. We need people with all different skill sets to help turn this event into the money-maker and awareness vehicle we know it can be. For more information, contact Diann Peterson at 800-777-8189 or at diann.peterson@spondylitis.org.

AUCTION your own items via eBay's GivingWorks on SAA's behalf. Perfect for veteran eBayers who already know the ins and outs of online auctions. Just designate a portion of the sale price to benefit SAA.

MAKE SAA the beneficiary of your wedding, birthday party, anniversary celebration, etc. You're already planning the party – why not ask your guests to help support your favorite cause?

SOLICIT friends and family, encouraging them with the value of donating to SAA.

ENCOURAGE local businesses to donate a portion of a day's proceeds to SAA. Many businesses have a percentage of their budget set aside for charitable giving. Why not bring SAA to their attention?

DOES your employer match charitable contributions? If so, your donations can go twice as far. If your employer doesn't have

a matching gift program, perhaps you can spearhead the project.

TELL us your story. Many spondylitis patients benefit greatly from the experiences of others who know what they're going through. Both Spondylitis Plus and www.spondylitis.org are always looking for fresh stories from patients, but also from parents, spouses, children, friends and colleagues of those with spondylitis. If you think that you have a unique story to tell, please contact Laurie M. Savage at laurie.savage@spondylitis.org

Not all worthwhile contributions to SAA are monetary. If there's no support group in your area, you might consider starting one. It's a wonderful way to have a direct, positive impact on the lives of others in the AS community. For more information about support groups, contact Melissa Velez toll-free at 800-877-8189, ext. 227 or email Melissa.velez@spondylitis.org.

Together, SAA's members and donors, volunteer fundraisers, corporate partners and foundation supporters are ensuring that SAA will continue to provide programs and services until the day we help – together – to uncover the cure.

Maximizing insurance coverage for TNF-alpha blockers

By Scott P. Edwards

Unlike many patients with ankylosing spondylitis (AS), Patrick Murphy and Mike Supancich know a little bit about the healthcare and pharmaceutical industries. Murphy, of suburban Chicago, is an account manager for a pharmaceutical company. Supancich, who lives in the San Diego area, is a retired ophthalmologist. Their jobs, obviously, bring them through the trenches of the arcane, complex and, for many, confusing constellation of health insurance programs in the marketplace. Most AS patients or those with other spondyloarthritis diseases don't have the same background, so navigating the insurance waterways can be difficult at best and sometimes nearly impossible.

During the SAA's recent Patient Educational Seminar in Chicago, there was considerable discussion among attendees about the challenges of insurance coverage, especially as it relates to the powerful and very expensive medications now approved for AS and several related diseases. As many people currently experience, the biologics or TNF-alpha blockers can cost, even with insurance, up to and more than \$500 per month. This high out-of-pocket cost presents a very serious burden for many people.

Because there are so many different health insurance plans, policies and premiums with different drug formularies (lists of medications that are usually covered by a health plan), the physicians who prescribe these drugs are often not able to gear their decisions about medical management of this group of diseases—or any other for that matter—to an individual's coverage.

This article is the first in a series of articles that are intended to help spondyloarthritis patients better understand what they need to know about their health benefits and how to use available resources in order to maximize their insurance coverage, especially if they are on high-cost biologics.

Real-Life Experiences

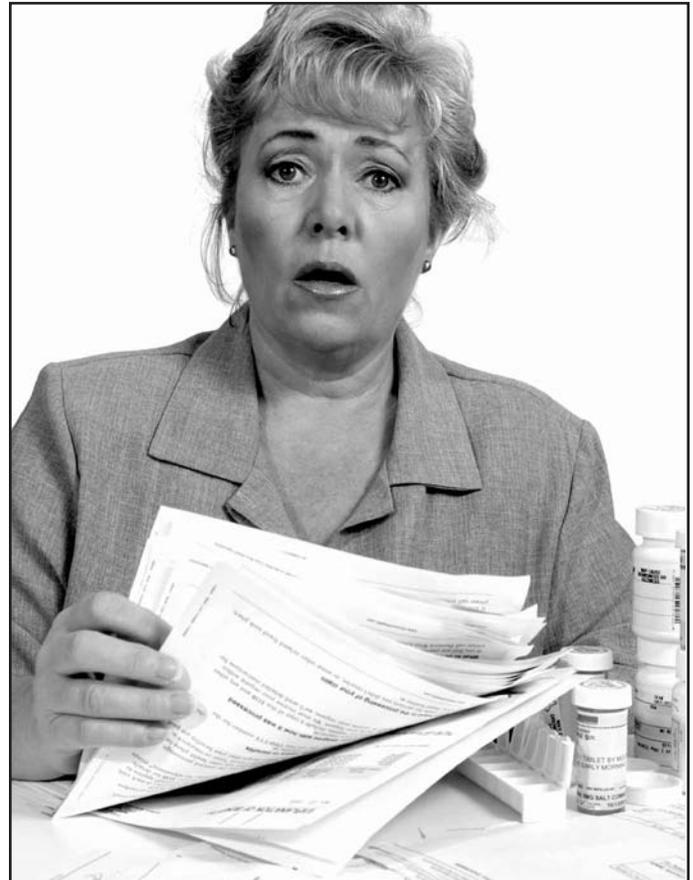
Mike Supancich, a retired ophthalmologist from Carlsbad, Calif., has lived most of his 63 years with AS and, hence, has lots of experience with

The issue of whether continuous treatment is necessary to keep symptoms at bay was explored in a German study, which was conducted several years ago. The researchers found that over time, once the drugs were stopped, the AS symptoms returned in 100% of the patients.

the different therapies that have come and gone since he diagnosed himself with AS early on in medical school. These include Methotrexate, Oral Prednisone and phenylbutazone (Tanderil®), which up until the development of the biologics was the most effective drug in treating the more severe symptoms of

AS for many people. Phenylbutazone is still available through compound pharmacists but went off patent many years ago, partly due to undesirable, serious side-effects.

Then came the biologics. For more than five years, starting in January 2000, Supancich took twice-weekly injections of a biologic,



which he says truly changed his life, but then became less effective over time. Dr. Supancich was then switched to two monthly injections of one of the other biologic drugs, which he says have been very effective. (Potential reasons for diminishing efficacy are discussed in the Q&A section of this issue, page 6-7.)

Who Will Pay?

While effective, TNF-alpha blockers present patients with a daunting challenge: how to pay for them. These medications can cost up to \$25,000 per year, and they need to be taken on a continual basis in order to remain effective.

As is the case for many, Mike Supancich's out-of-pocket costs associated with the biologics have varied greatly over the years. With good health insurance, Supancich has paid as little as \$12 per month, and with not-so-good coverage, up to \$200 per month for his TNF-alpha blockers. He currently pays \$100 each month, but anticipates that in line with other prescription medications whose costs have risen dramatically in recent months, "A significant increase in the monthly copay is very possible," he says, "if not now, soon."

Compared to Supancich, Patrick Murphy is a newcomer to AS. The 37-year-old father of four was diagnosed with AS just last August during the week his wife gave birth to the couple's fourth child. Murphy had suffered knee pain for years. In fact, he underwent knee arthroscopy because his orthopedist thought he might have cartilage damage. He also suffered

unexplained joint pain. For nearly two years, he suffered from a swollen joint in his hand. His doctor thought he had rheumatoid arthritis, so he referred Murphy to a rheumatologist, who diagnosed the AS.

Murphy's doctor prescribed several different classes of drugs before settling on a biologic. In January 2006, he was prescribed one of the self-injectables approved for AS, which so far, he says, is going well. "Parts of my body that hurt for years," he says, "no longer hurt."

Both Murphy and Supancich get their TNF-alpha drugs through mail order houses. In some cases, this approach saves money—for Murphy, about \$720 for a three-month supply. In addition to the potential savings, mail-order pharmacies also handle prescription reauthorizations, sparing patients the often-maddening round of telephone calls this process entails. This is not, both men caution, buying prescriptions from Canada; rather, it's an option for people using chronic medications like TNF-alpha blockers, blood pressure drugs and others, giving them the ability to have prescriptions processed and filled at a facility and mailed to them.

Keys to Success

The key for AS patients, say both Murphy and Supancich, is to understand what is and what is not covered under one's health insurance. That means knowing who pays for the medical portion of the insurance (for doctor visits and medical care) and who pays for prescription medications.

"It is important," says Murphy, "for a person to understand how their benefit design works and what it provides for drugs, as well as medical costs. What often happens is that most people know little about their medical benefits and expect or want their physician to know their plan. Knowing the specifics about your benefit plan may lead to reduced anxiety, which, in turn, helps manage the condition."

AS patients should take advantage of their employer's "open enrollment period." This is the one time per year when employees can evaluate their health coverage and either change the plan they have or switch to another insurance company altogether. When comparing plans, ask insurance providers what the costs will be if a TNF-alpha blocker is prescribed.

Most plans today cover a percentage of the cost of these drugs and require a co-pay from the patient for the remainder. Medicare, the health insurance program for people over age 65, helps to cover the cost of Enbrel, Remicade and Humira; however, pre-authorizations for prescriptions are often required. All state Medicaid programs help with the cost of TNF-alpha blockers.

"Most people know their cable bill better than their health insurance coverage," says Murphy. "There are things that a person living with AS or a related disease should educate themselves about, including knowing how their medications are paid for."

Each of the three major TNF-alpha manufacturers (Immunex Corp. for Enbrel, Centocor for Remicade, and Abbott Laboratories for Humira) has a pharmacy benefit assistance program to help patients with questions about their medications and insurance coverage.

Enbrel's Enliven Services (1-888-4ENBREL; www.enbrel.com) provides assistance with prior authorizations, the appeals process for needed benefits, and yearly insurance recertifications, as well as referrals to specialty pharmacies and benefit education materials.

Remicade's AccessOne program (1-888-ACCESS-1; www.remicade.com) provides a wide variety of information about insurance coverage from Medicare, Medicaid, managed care plans and traditional health insurance.

We urge you to visit us at www.spondylitis.org for additional resources and support via our message boards. Check out the special members' section by logging in with your email address and zip code. Find support groups located around the country at http://www.spondylitis.org/patient_resources/support_groups.aspx

What are the biologics and how do they work?

People with AS have too much of a substance called tumor necrosis factor-alpha, or TNF-alpha, in their bodies. TNF-alpha is a proinflammatory cytokine, a group of small proteins released by cells throughout the body that play a critical role in controlling inflammatory and immune responses. In high amounts, TNF-alpha attacks healthy body tissue and causes inflammation in the bones, cartilage, joints and entheses, which is where the ligaments insert into the bone and is considered the hallmark of ankylosing spondylitis.

Humira is part of the Partnership for Prescription Assistance (1-888-4PPA-NOW; www.pparx.org). This program, sponsored by U.S. pharmaceutical research companies, provides a "single point of access to more than 475 public and private patient assistance programs that could offer help on more than 2,500 prescription medications," according to an organization press release.

There are also numerous disease management programs available, says Murphy, through which patients can speak with a nurse or case manager about their condition. These programs are designed to "improve the health of people with specific chronic conditions and to reduce healthcare service use and costs associated with avoidable complications, such as emergency room visits and hospitalizations," according to a paper published by the Center on an Aging Society at Georgetown University. Disease management programs usually include a collaborative practice model, including physicians, nurses, pharmacists, dietitians and other caregivers who help patients manage their condition, as well as patient self-management education programs.

Murphy says that people with spondyloarthritis should check with their employer to see if their health insurance covers this benefit.

Resources for Patients and Families

Dr. Supancich, an SAA Board Member, runs the SAA Carlsbad, Calif., Patient Educational Support Group. He says these support groups provide a comfortable, friendly environment in which to share information about AS, as well as the trials and tribulations of dealing with insurance companies. In fact, he says, "the most common issue in our support group is the ability to pay for medications such as TNF-alpha blockers."

In the end, say Supancich and Murphy, spondyloarthritis patients have to be their own advocates—in managing their disease and maximizing their insurance benefits.

"You can't just throw your hands up," says Murphy. "It's your condition; you have to know as much about it as you can and how it affects your health coverage. It's a total approach to healthcare. You have the disease and you are on meds for the rest of your life. You need to understand the disease progression and drug side effects. You need to manage your disease, and part of that is knowing your health insurance coverage."



SAA Provides Training to Leaders

On a beautiful weekend in early May, seventeen educational support group leaders from around the country came to Los Angeles, CA to participate in SAA's first-ever Educational Support Group Leader Training. It was an opportunity for the leaders to meet face-to-face, meet SAA staff, and receive information on a variety of issues important to their group members and to their roles as facilitators. Over the two-day training, Leaders attended the spondylitis educational seminar (highlighted on pages 6-7) and participated in an all-day training session with featured presentations on chronic disease self-management and tools to effectively facilitate group discussions.

This training was a huge success, in part due to the dedication and commitment of these support group leaders. We know that these groups provide education and information, emotional support and allow for open discussions about living with spondylitis. SAA is dedicated to providing resources, training and guidance to these groups to help them to be as successful as possible.

In the News

An article featuring Alex Best, Myrtle Beach, SC Group Leader, and his struggles with AS recently appeared in the Vitality section of the Myrtle Beach Sun News. To read the article, go online to www.myrtlebeachonline.com/131/story/125968.html.

Group Meeting Highlights

- At a recent Washington, DC Spondylitis Educational Support Group meeting, Dr. Neil Constantine gave a presentation on Immune System Involvement in AS and Related Conditions.
- Dr. Patrick Knibbe spoke at the Boise, ID Group's May meeting and provided members with an "excellent background on this group of conditions and answered many questions".
- Carol Lemieux, a Personal Trainer and Physical Therapist Assistant from the Michigan Institute of Human Performance, recently demonstrated

Photo Top Left: Alex Best. Top Center: Craig Gimbel. Top Right: Roger Stead. Below Group: From left to right: Ken Prather, John Kornfeind, Roger Stead, Howard Tevelson, Frances Tomich, Barbara Crofut, Michelle Andrews, Elizabeth Smith, Ken Henschel, Scott May, Richard Powell, Kyle Brownfield, Linea Cooley, Paul Stevenson, Melissa Velez, Mike Supancich, Alex Best, Jamie Myler.

movement exercises at a Detroit, MI Group meeting. Carol's husband has AS and she has worked with him to successfully increase his range of movement while decreasing his pain. As one member expressed, Carol helped members get excited about stretching and exercise!

Introducing Dr. Craig Gimbel, new Spondylitis Educational Support Group Leader for Summit, NJ

Dr. Gimbel resides in Denville, New Jersey with his wife Ruth, son Alex and his Bichon Frise dog, Frisky. He received his dental degree from New York University in 1977 and has completed Advanced Proficiency laser certification, and is member of several professional dental organizations. He sold his dental practice after 27 years due to his spondylitis and is now involved in dental research and development. He is the current President of the Academy of Laser Dentistry and has been an Invited Lecturer to Dental Meetings around the United States and the world, including Puerto Rico and Israel.

Since 2003, he has been a Volunteer Scuba Diver for the New Jersey State Aquarium; he presents underwater talking dive shows, assists marine biologists, and tests and trains new volunteer scuba divers.

Craig has a love for sharing his knowledge with others and giving the opportunity for others to learn. He hopes to establish a strong spondylitis educational support group in the metropolitan northern New Jersey/New York area.



SAA Receives Donations From Crüefest Annual Music Benefits

We are pleased to announce that we recently received donations from CRÜEFEST CHICAGÖ and NEW ENGLAND CRÜEFEST.

CRÜEFESTS are annual music benefits which take place throughout the U.S. and Canada to raise funds for the charities of Motley Crue band members. Mick Mars, Motley Crue's guitarist, designated the Spondylitis Association of America (SAA) to receive proceeds from the concerts.

CRÜEFEST concerts are organized and run by a small group of volunteers in the various cities where the concerts are held. The daylong benefits feature bands who donate their talent, as well as raffles and auctions which include guitars and a variety of merchandise signed by members of Motley Crue. The highlight of the events is the opportunity for Motley Crue fans to get together and raise funds for the band's charities.

We want to extend our gratitude to the volunteers and fans of CRÜEFEST CHICAGÖ and NEW ENGLAND CRÜEFEST for their efforts to raise awareness and funds for the Spondylitis Association of America. We especially want to acknowledge Mick Mars for including SAA as a beneficiary of the CRÜEFEST concerts



Photo Top Right: Elizabeth Smith. Center: John Kornfeind. Bottom Group: CRÜEFEST volunteers.

NEW ONLINE POLL

You can find a link to our newest informal survey about participating in research studies on our website at www.spondylitis.org., where you will be directed to our online survey created by SurveyMonkey.com. We will continue to report the results in Spondylitis Plus.

RESULTS FROM SUMMER 2007 ONLINE POLL:

How is your work life affected by spondylitis?

WHAT IS YOUR AGE?

13 – 19	0.5 %
20 – 29	9.8 %
30 – 39	19.6 %
40 – 49	32.7 %
50 – 59	24.8 %
60 +	12.6 %

HOW LONG AGO WERE YOU DIAGNOSED WITH SPONDYLITIS?

Recently diagnosed (less than one year)	21.5 %
1 – 3 years ago	21.5 %
3 – 5 years ago	8.4 %
5 – 7 years ago	5.1 %
7 + years ago	35.1 %
I have not received an official diagnosis	8.4 %

WHICH BEST DESCRIBES YOUR CURRENT OCCUPATION?

I work full-time	47.2 %
I work part-time	9.4 %
I currently do not work outside of my home.	36.5 %
I am self-employed.	7.0 %

HAS SPONDYLITIS NEGATIVELY IMPACTED YOUR OCCUPATION?

Yes	74.3 %
No	25.7 %

IN THE PAST TWO MONTHS, HOW OFTEN HAVE YOU MISSED WORK DAYS DUE TO SPONDYLITIS?

0 days	44.4 %
1 day	10.8 %
2 days	7.5 %
3 days	4.2 %
4 days	4.7 %
5 or more days	25.5 %

I HAVE MISSED WORK RELATED TO MY SPONDYLITIS BECAUSE OF:

Pain	65.0 %
Fatigue	50.9 %
Treatment Appointment with Physician	34.1 %
Other includes:	22.0 %
Have not missed work	24 %
Retired or on disability	36 %
All of the above	6 %
Other Medical Issues	34 %

SAA Members' Survey Responses Published

Earlier this year, Dr. Walter Maksymowych contacted the SAA for assistance with an online survey. He was seeking to determine to what extent the BASDAI and BASFI address the most essential symptoms and disabilities of AS.

The BASFI and BASDAI questionnaires are sometimes used as self-reporting mechanisms in the rheumatology office to track disease progression and functioning in the individual.

As always, SAA members stepped up to the plate, and this time, via online links and email, over 800 hundred responses were returned. We are delighted to tell you that from these results, Dr. Maksymowych wrote a paper that was presented at the recent EULAR research meeting in Europe and that has been submitted for presentation at the upcoming ACR Scientific Meeting in Boston.

Dr. Maksymowych's survey results suggest that only a minority of AS patients believe that the BASDAI and BASFI completely address their main symptoms and disabilities and that the majority think that additional items may be useful in improving the effectiveness of these instruments.

If you would like to find out more about the BASDAI and BASFI scoring systems, please visit the SAA website at www.spondylitis.org/physician_resources/assessment.aspx

SAA is coming to your city soon!

The SAA is continuing to expand the scope of its Patient Educational Seminars nationwide. To this end, we have seminars scheduled in the following cities:

- September 29, New York, NY
- October 13, Seattle, WA
- February 9, 2008, Atlanta, GA

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

AREA	FACILITATOR	EMAIL	PHONE
Little Rock, AR	Mindy Hunter	mindy.hunter@sbcglobal.net	(501) 351-6374
Phoenix, AZ	John Kornfeind	jmmkorn@cox.net	(623) 910-4742
Long Beach, CA	Barbara Crofut	crofutgr@verizon.net	(562) 421-9698
Long Beach, CA	Frances Tomich	not available	(562) 429-9685
Orange County, CA	Kyle Brownfield	kylebrownfield@msn.com	(949) 367-0430
San Diego, CA	Mike Supancich	supancichsr@roadrunner.com	(760) 438-2962
San Francisco, CA	Eric Passmore	eric.passmore@gmail.com	(510) 644-0864
Denver, CO	Jennifer Visscher	jvisscher@myedl.com	(303) 478-9985
Stamford, CT	Christine Wu	cwu108@yahoo.com	(914) 837-1190
Washington, DC	Roger Stead	rogerstead@aol.com	(703) 455-6005
Savannah, GA	Wil Carswell	wilcars@yahoo.com	(912) 858-4651
Boise, ID	Cindy Salo	csalo11@hotmail.com	(208) 850-3313
Chicago, IL	Joyce Terzick	alden41@aol.com	(815) 744-5017
Chicago, IL	Kim Klinko	kimklinko@hotmail.com	(312) 237-6179
Fort Wayne, IN	Ken Prather	pratherken@yahoo.com	(260) 637-1705
Indianapolis, IN	Ken Prather	pratherken@yahoo.com	(260) 637-1705
Kansas City, MO	Linea Cooley	linea_cooley@hotmail.com	(913) 384-0728
Augusta, ME	Michelle Andrews	qualey28@roadrunner.com	(207) 445-2885
Portland, ME	Penny McAuley	spondylitis.portlandmaine@yahoo.com	(207) 878-9414
Detroit, MI	Laura Russell	mrussell.21@netzero.com	(586)-530-9988
Grand Rapids, MI	Scott May	smay@wmis.net	(616) 610-9130
Long Island, NY	Roni Figueroa	fourthever@aol.com	(631) 334-1655
Summit, NJ	Craig Gimbel	believe5154@optonline.net	(937) 476-8976
Portland, OR	Ken Henschel	Ken.Henschel@comcast.net	(503) 579-8375
Pittsburgh, PA	George Coppola	georgecoppola@msn.com	(412) 884-6919
Myrtle Beach, SC	Alex Best	alexbest@sc.rr.com	(843) 655-9762
Dallas, TX	Elizabeth Smith	elizabethsmith@dcccd.edu	(972) 860-7179
Houston, TX	Richard Powell	rwpowell@gt.rr.com	(409) 883-7822
Houston, TX	Stephen Haskew	haskews@verizon.net	(281) 337-3997
Richmond, VA	Sam Brumberg	Samuel.Brumberg@LeClairRyan.com	(804) 968-2981
Seattle, WA	Paul Stevenson	paul-megan@msn.com	(206) 524-2186
Spokane, WA	Joan Polzin	joanp115@webband.com	(509) 624-8214

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

ONLINE SUPPORT



Looking for someone to talk to? Want a supportive atmosphere to ask questions, discuss symptoms, medications, or do you just need to vent? Then visit the Spondylitis Association of America's Message Boards on spondylitis.org:

<http://bbs.spondylitis.org/cgi-bin/ultimatebb.cgi>

Recent topics have included:

- Ancestry & AS
- Hip Pain
- Remicade
- And more.

The SAA forums are your 24/7 place for support.

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Donate A Car Today And Help Advance Research Tomorrow!

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@cshs.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

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 or at 800-877-8189, ext. 229.

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

**LOG IN
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



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