Major Breakthrough in Genetic Research

Music, Medicine and Giving

SSI Disability in Five Easy Steps
Reflecting upon the past twelve months, I am reminded that riches come in many forms and that the people who have touched our lives with friendship and support, and to whom we owe much, are a treasure whose value is not easily quantified.

Here at SAA we have much to be grateful for this past year. During a year when many nonprofits were forced to cut programs and services, SAA expanded the scope of its efforts. That would not have been possible without the dedication and generosity of so many individuals, sharing their talents, creativity, personal resources, sacrifice and hard work in support of those affected by spondyloarthritis.

I am proud to be part of this community, and to enjoy the leadership of our Board of Directors and the scientific stewardship of our Medical and Scientific Advisory Board. Thank you.

Let me share a few of our most recent endeavors:

- Drs. Reveille, Brown and colleagues’ continued efforts in advancing spondylitis genetic research and the acceptance of their most recent paper in the prestigious journal, Nature Genetics;
- the production, accreditation and dissemination of the Emergency Medical Services First-Responders training video;
- the publication of the “Screening Tool for AS” manuscript in the January 2010 issue of Arthritis Care and Research;
- our new collegial relationship with Dr. Alfonse Masi, who is exploring a novel hypothesis regarding a potential biomechanical trigger in AS;
- earning our own Facebook® URL due to having more than 1,000 active members;
- new YouTube Charity Channel/donation portal;
- a segment on ABC News7 in NYC with Dr. Jay Adlersberg;
- three years as Oprah’s “high mark” charity pick in the field of arthritis;

These things are good, but there is a lot more work to be done. And now, onward, with gusto, into 2010!

Sincerely,

Laurie M. Savage
Executive Director
An Attitude of Gratitude

Until I connected with the Spondylitis Association of America, I did not have anyone who understood what I was going through, other than my father, and AS affected us totally differently as it usually does with men and women.

Some may think I am a victim because I want to share with others who have similar experiences, but chronic pain does affect you, physically, mentally, and emotionally. For me the hardest part has been the emotional and mental toil to live a life half full, not half empty, even when you are in pain. I have a very positive attitude, but some days are very hard. I say I am empowered by the knowledge that I share with others. You can have a good life even with AS, but for me, it is wonderful to have others who understand. Chronic pain has given me an attitude of gratitude when the days are good, and SAA has given me a group to know I am not alone.

True acceptance of my disease has been the key to my serenity. Someday there may be a cure for AS, but today I accept that I have AS and it HAS changed my life. And I thank SAA for the support of so many who understand what I have when so many do not.

PHOEBE R.

Start Spreading the News

Your upcoming spondylitis awareness campaign recently got me thinking of how I was personally impacted by the ignorance of AS in the medical community during the 10 years before my diagnosis. Even though I had visited seven different doctors over those years, some even specialists, never once was AS even a consideration or mentioned. Ironically, my doctor had recently had a friend that had been diagnosed with AS and he was somewhat familiar with his friend’s symptoms. While I’d been seeing him for years, he happened to notice that I was consistently complaining of the same problems and they were similar in nature to his friend’s symptoms. He ran the HLA-B27 test and it came back positive. The rest was, as they say, history.

ROB P. from Panama City, FL

It’s All in the Genes

I just read the press release from the University of Texas at Houston that SAA kindly emailed me. Congratulations are in order to you, Drs. Reveille and Brown and to your entire research team for your work on DNA chromosomes. Your continued research is bringing us closer to an early diagnosis, prevention and cure for AS, sooner than we could have ever imagined. Thank you on behalf of all those affected by AS worldwide. (see article on page 4)

CRAIG GIMBEL, DDS
SAA Board Member and AS patient

READERS’ FORUM

An Attitude of Gratitude

Dear Readers:

We want to hear from you, whether it be informative, uplifting or a concern 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 the Editor/SAA
P.O. Box 5872, Sherman Oaks, CA 91413
Work done by the Triple “A” Spondylitis Consortium (i.e. the TASC or Australo-Anglo-American Spondylitis Consortium) has led to the discovery of two new genes that are implicated in ankylosing spondylitis (AS). In addition, the international research team pinpointed two areas along stretches of DNA that play an important role in regulating gene activity associated with the arthritic condition.

The findings, a critical milestone in the understanding of AS, are published in the January 2010 issue of *Nature Genetics*, a journal that emphasizes research on the genetic basis for common and complex diseases. “This helps us better understand what is driving this disease and gives us direction for new treatments and diagnostic tests,” said John D. Reveille, MD, the study’s principal investigator and professor and director of the Division of Rheumatology and Clinical Immunogenetics at The University of Texas Medical School at Houston and a Member of SAA’s Board of Directors.

Reveille, the university’s Linda and Ronny Finger Foundation Distinguished Chair in Neuroimmunologic Disorders, and Matthew A. Brown, M.D., professor of immunogenetics at Australia’s University of Queensland, led the research conducted by the TASC Genetic Study.

The Spondylitis Association of America has been a long time collaborator in this study, first acting as the clinical coordinating center for the effort and then leading the nationwide recruiting efforts to provide the patient population to participate in the research project.

Based on results from a genome-wide association scan, the team identified genes ANTXR2 and IL1R2 as well as two gene deserts, segments of DNA between genes, on chromosomes 2 and 21 that are associated with ankylosing spondylitis. Importantly, the study also confirmed TASC’s previously reported associations of genes IL23R and ERAP1, (formerly known as ARTS1) that were published in 2007. These two genes have been extensively confirmed by groups in Spain, Canada, England and Asia, and have been shown to be critical in influencing the immune system and setting the background for AS susceptibility.

Laurie Savage, co-principal investigator and Executive Director of the Spondylitis Association said, “These new breakthroughs are, indeed, good news for those we serve. It is very encouraging to know that the health impact and economic consequences of spondyloarthritis in the world eventually will be contained as a direct consequence of the dedication of Drs. Reveille, Brown and colleagues, and that of the many individuals affected by spondyloarthritis who have participated in these studies.”

The Centers for Disease Control and Prevention for the National Arthritis Data Workgroup estimates that AS and its related diseases affect as many as 2.4 million people in the United States, which is considerably more than current estimates for rheumatoid arthritis. “All the more reason to redouble our efforts to attract potential funders and drive promising young researchers to this critical field of study,” says SAA’s Savage.

The TASC Study is supported in part by grants from the National Institute of Arthritis and Musculoskeletal and Skin Diseases.
A Comparison of Cardiovascular Risk in Patients with Spondyloarthritis (SpA) and Rheumatoid Arthritis (RA)

Purpose:
The management of cardiovascular disease (CVD) and its risk factors plays an important role in the management of individuals with inflammatory arthritis (IA). The British Society for Rheumatology and The National Institute for Health & Clinical Excellence (NICE) both recommend that patients with IA should be offered annual CVD review. The medical literature suggests that the multiplier risk in both RA and SpA is 1.5 times greater than in the general population. The researchers set out to study whether or not there was an adequate need prior to developing a screening procedure for CVD in both RA and in SpA.

Method:
RA patients and SpA patients, without diabetes or CVD were recruited over a five week period in two consecutive years. Ten year CVD risk was calculated using the Joint British Societies risk calculator and comparisons were made between the two groups. Both sets of data were multiplied by 1.5. Paired tests were then used to compare risk scores within each disease group.

Conclusion:
CVD is an important cause of mortality and morbidity in IA. Disease burden is underestimated by standard risk assessment. Multiplying by 1.5 is an acceptable estimation of true risk. This, however, significantly increases the number of patients requiring primary prevention in this area. This should be recognized when establishing such services.

References:
(2) Gladman, D.D., Ang, M., Su, L., Tom, B.Dm, Schentag, CT & Farewell, VT. Cardiovascular morbidity in psoriatic arthritis (PsA). Annals of the rheumatic diseases. 09/2008 ARD Online First, 10.1136/ard.2008.094839

A Tale of Two Cities; The Effect of Low Intensity Conflict On Prevalence and Characteristics of Musculoskeletal Pain Associated with Chronic Stress

Purpose:
Although the medical literature suggests that both acute and chronic stress can lead to pain, the precise characteristics of this association have not been defined. A group of researchers in Israel sought to explore this issue by studying the effect of stress on the people of two townships.

These two towns were Sderot and Ofakim. Sderot is an Israeli town exposed to repeated missile attacks. Ofakim, a town of similar demographic and socioeconomic characteristics, had not been targeted, as of the period of this study. The researchers set out to explore the occurrence and characteristics of pain and related symptoms in Sderot and Ofakim and to compare them.

Method:
1,750 households were contacted by telephone in Sderot and 1939 in Ofakim, with a 59% and 52% participation respectively. A total of 2,030 interviews were conducted.

1,024 individuals in Sderot and 1,006 in Ofakim were interviewed regarding pain, somatic symptoms, mood, trauma - exposure, and general health status.

Results:
Significantly higher levels of trauma-related symptoms and somatic symptoms were noted in Sderot compared with Ofakim, including chronic widespread pain and chronic regional pain.

Conclusion:
The researchers concluded that this study demonstrated that the effect of ongoing missile attacks on the civilian population of Sderot were evident. There were significantly increased rates of physical complaints, including pain, fatigue and IBS-like symptoms, as well as significantly higher rates of trauma-related symptoms. Widespread pain was reported significantly more frequently by inhabitants of Sderot compared with Ofakim but was not independent of increased self-reported depression. The results highlight the contribution of external “environmental” factors such as stress to the occurrence of chronic pain. It remains to be investigated to what extent these external factors may interplay with a genetic predisposition.

References:
The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Coalition is a group of professional and voluntary organizations concerned with NIAMS programming. On Nov. 3, the Coalition held its 2009 Outreach & Education Meeting in Bethesda, MD., giving members an opportunity to network and share best practices on the importance of connecting science to the public. As a member of the Coalition’s Steering Committee, SAA Executive Director Laurie Savage is playing an active role in advocating for increased research funding for spondylitis.

As part of his State of the Institute address, NIAMS director Dr. Stephen I. Katz discussed the Institute’s mission, as well as the current status of stem cell research, studies of rare diseases and clinical trials and partnerships. A key goal of the Institute, he said, was to engage the public to educate those who could benefit from NIAMS research and to communicate research goals and findings in easy-to-understand language. Essential to achieving this goal, he added, was the combined involvement of scientific, professional and voluntary communities, including the NIAMS Coalition.

Two other NIAMS executives - Dr. Robert H. Carter, Deputy NIAMS Director, and Anita Linde, Director of the NIAMS Office of Science Policy and Planning - also provided information on NIAMS’ efforts. Carter discussed the impact of the American Recovery and Reinvestment Act of 2009 - the federal stimulus plan on research, while Linde outlined five core topic areas and described the importance of NIAMS collaborations and partnerships included in NIAMS’ long-range plan for FY 2010-2014.

During the keynote address, the Hon. John Edward Porter, Chairman of Research!America, a not-for-profit public education and advocacy alliance that seeks to make health care research a high national priority, spoke about the importance of supporting health science research.

He described how, as a U.S. Congressman, he worked to double the NIH budget, advocating for building bridges between the public and the scientific community, as well as between the political and scientific communities.

Janet Austin, NIAMS Director of Communications and Public Liaison, described NIAMS’ communication vehicles, including brochures, fact sheets, electronic newsletters and print publications, all of which are free. She also discussed NIAMS’ recent collaboration with “CBS Cares” and the producers of the Tony Award-winning musical “Hair” to produce public service announcements about bone health, as well as an initiative called “Best Bones Forever,” geared toward girls ages 9 to 16.

Best practices were the focus of the afternoon breakout sessions, providing Coalition members the opportunity to share and learn. One session focused on the importance of collaborating with other organizations, supporting young investigators, and building partnerships with federal agencies to promote clinical support. Another addressed the development and dissemination of research-based information, with several members sharing the materials their organizations have adopted for specific audiences.

By actively representing the unmet needs of the spondylitis community at conferences such as these, SAA is working to increase federal funding for spondylitis research, encourage young researchers and clinicians to enter the field and promote awareness that will lead to earlier diagnosis and better treatment modalities.
Jim Hall was living in Rochester, New York, working in the theater with his wife, Bonnie, in 1975 when he was diagnosed with ankylosing spondylitis (AS). Taking the “gypsy road of theater life,” Jim and Bonnie moved from New York to Maine, then to Colorado, and finally settled in southern California, where they live now, in Carlsbad.

Treated initially with ibuprofen and naproxen, Hall eventually developed kyphosis, a progressive disorder in which the normal curves of the spine become malaligned, causing a head-on-chest posture. The disorder is characterized by a rounding of the upper back – sometimes exaggerated to as much as 40 to 45 degrees – and may include such symptoms as back pain, spinal stiffness, and fatigue. Kyphosis causes not only cosmetic problems and a loss of forward gaze, but also disrupts the normal biomechanics of the spine.

Surgery for kyphosis is usually the last treatment option. Surgery is generally considered if the curve severity of the kyphosis is greater than 80 degrees in the thoracic spine (mid-back) or 60 degrees to 70 degrees in the thoracolumbar spine (mid-back to low-back); if the kyphosis gets progressively worse, despite non-surgical treatments; if the patient has balance difficulties because of the curvature of the spine; or if the kyphosis is causing neurological symptoms such as weakness, numbness, tingling or bowel or bladder dysfunction.

Surgical techniques, such as pedicle subtraction with osteotomy (PSO), are designed to facilitate the correction of spinal deformities, including kyphosis. Through a Spondylitis Association of America support group, Hall learned of the work being done by Dr. Brian Perri, an orthopedic surgeon at Cedars-Sinai Medical Center in Los Angeles, to help people suffering from the devastating progression of AS and kyphosis. In 2007, Dr. Perri performed a PSO procedure on Hall to correct the deformity caused by his kyphosis.

Jim Hall recently spoke with Spondylitis Plus about his life with AS, his pedicle subtraction surgery, and how he is faring after the surgery.
When were you diagnosed with spondylitis and how were you initially treated?
I was diagnosed with AS in December 1975, while I was living in Rochester, New York.

I had some fusing in the hip and bamboo spine [the rigid spine produced by AS]. My doctor told me to take non-steroidal anti-inflammatories (NSAIDs) and to try to stay upright as much as possible. He basically said, “good luck,” and little else. He also told me that AS would do whatever damage it would by the time I turned 40 and then I’d be in remission. I remember that very clearly. I didn’t know what to think.

There was not much treatment early on. I just kept living my life, taking ibuprofen, doing acupuncture, holistic medicine, yoga, stretching, basically anything to feel better. My primary care physician put me on a different NSAID in 1994, which gave me some relief, but it didn’t stop the deterioration of my spine. I was doing theater, rolling and tumbling on stage, but I could see later from publicity photos that I was starting to develop kyphosis in the early 1970s.

I continued working in theater, moving to southern California in 1981, with my wife Bonnie and my two daughters. We ended up moving to Encinitas and then to Carlsbad, where I worked in community theater and was the manager and community liaison for the Carlsbad Unified School District, managing a 400-seat theater for the school and community. I did that for 23 years until I retired.

Soon after I retired, I had an unusual fainting spell. I went to see a neurologist and he said I needed to go see Dr. Roy Kaplan, a rheumatologist in Encinitas, one of the best in the business. Dr. Kaplan followed me for years, finally putting me on a TNF blocker in the fall of 2004.

You developed kyphosis in the early 1970s, but it wasn’t until many years later that it became a real problem. What happened?
I fought a good battle against kyphosis and was pretty straight until about the late 1980s. Then a bunch of family things hit: my stepmother was diagnosed with fairly aggressive Alzheimer’s disease and my father developed prostate cancer. There was a great deal of stress and aggravation in my life. I stopped doing yoga, put on a tremendous amount of weight, and my kyphosis kept getting worse. I was bent forward about 17 centimeters. I used a three-wheeled walker to get around the house and to take my dog for a walk. I used walking sticks to help me stand up straight.

“When my best advice would be to ask every possible question you can. Get in touch with support groups to find people who have had this surgery, and ask them everything you possibly can.”
In 2004, I joined an SAA support group and met Michael Supancich [a retired ophthalmologist who serves on the SAA Board of Directors and is an SAA support group leader]. I spent time with Michael, having lunch with him and attending support group meetings. He knew I was in a lot of pain because he himself had had spinal surgery 10 years earlier for stenosis. I am so fortunate to have the resources of the SAA support group. Mike told me about Drs. Brian Perri and Khawar Siddique at Cedars-Sinai Medical Center and the work they were doing for AS patients and people with kyphosis. He told me not to consider anyone but a team like this, a neurologist and an orthopedist. [Brian Perri, D.O., is an orthopedic surgeon and Khawar Siddique, M.D., is a neurosurgeon.]

You had a procedure called pedicle subtraction with osteotomy. What was that experience like?

Once I learned about the surgery, I decided that it was the appropriate thing to do, pending insurance, and that it was something I couldn’t pass up. Prior to my operation, I met with Dr. Perri for meetings about the operations and a series of X-rays to determine if I had scoliosis along with kyphosis [he had only kyphosis]. There was a great deal of preparation for both me and the doctors. The procedure I had was called a pedicle subtraction with a closing osteotomy. Basically, they cut a lumberjack wedge in my lumbar spine in order to get my head over my shoulders. I read the statistics about the surgery and concluded I was safer under anesthesia and on the operating table than not.

After the procedure, I had to have some spinal nerves repaired in my lumbar spine. These were pinhole repairs to the sheath around the spine. My recovery was a little bit longer because of this. I spent two days in bed and, on the third day, with Dr. Siddique on one arm and Dr. Perri on the other, I walked for 15 minutes. I had no pain, and my shoulders were positioned over my hips. I was discharged after five days, with a body cast on my chest. I went through my recovery without much discomfort. Once I got off the morphine, I was good.

My neck surgery [to correct deformities in his cervical spine] was a little rougher. I needed two pints of blood and had some problems with the anesthesia. While this surgery was more difficult, in some ways it was less painful. I did have more side effects, like a broken shoulder, which resolved with physical therapy and exercise. I also had some ulnar nerve damage from how they had me strapped on the operating table. Basically, the ulnar nerve was being pushed against a bony area. Dr. Perri did a pedicle tunnel release surgery in September 2008 to fix the problem.

Would you recommend this surgery to other AS patients with kyphosis? What advice would you give them?

I would absolutely recommend this surgery. My best advice would be to ask every possible question you can. Get in touch with support groups to find people who have had this surgery, and ask them everything you possibly can.

Patients need to do a cost-benefit analysis before they have this surgery. It’s not only the money – and it’s not cheap – but when you come out of surgery, is your life better than it was before? Frankly, you’ll still have AS. You have to weigh the surgery and then weigh what it will be like when you come out of surgery. What would your life with kyphosis be like without the surgery? You only have to look at a picture [of people with kyphosis] and say, “Yes, cut me open and fix that.” If you’re 85 and your kyphosis is mild, why have the surgery? If you’re younger, using a walker, then certainly consider the surgery.

You also have to find the right doctors, the right medical team, and the right hospital. Ask everyone as many questions as you can and make sure you’re clear about the answers. Ask them if there are any questions you haven’t asked them yet. Back out if you’re not satisfied with what you’re hearing and find a new doctor. As the patient, you need to be in charge. You’re the one they’re working on.

It has been two years since your surgery. How are you doing now?

My surgeries are now far enough behind me that nobody knows there’s anything wrong with me. I still have some pain, but not as bad as I had with the kyphosis. I still have pressure on my optic nerve and some inflammation in my elbow and part of my back. But, you know, I love being able to look people in the eye and have a conversation with them. And I love being able to play with my grandson.

“I am so fortunate to have the resources of the SAA support group.”
As a teenager, I learned to sail on Lake Allatoona, near my hometown of Atlanta. Since the day I first sailed on Allatoona’s waters, I was taken. Sailing gave me a sense of freedom, a sense of focus amid the challenges of the teenage years. It also gave me a sense of purpose and commitment, and it became a focal point of my life.

Returning from military service, I raced hard for 25 years, competing in nearly 90 races each year. My wife, Peggy, crewed for me, and I never once beat her across the finish line!

Then, in 1968, my world came crashing down. One day I woke up and could not get out of bed. It took doctors nearly two years to diagnose my ankylosing spondylitis (AS). The diagnosis and resulting treatment changed my life. I was initially treated with NSAIDs and finally with a TNF-blocker.

Twenty years after my diagnosis, my spine was fused to the point that I could no longer race. Not wanting to give up my lifetime passion, I became very active as a race officer and sailing judge, working national, continental and world championship regattas across the world, including a major role in the 1996 Olympic Games Yachting. I recently took a one-year sabbatical from race management and judging regattas to run my local Rotary Club in Atlanta.

When I was diagnosed with AS, it, needless to say, had a major impact on my life. The big thing I noticed, however, was how little people really understood about the disease. Unlike other diseases, not much research was being done on AS and related conditions. Then, I found the Spondylitis Association of America (SAA).

I learned about SAA through my rheumatologist. I kept looking for people with AS in the Atlanta area, figuring that with a population of some 5 million people, at least a few had to have AS. When SAA came to Atlanta for an educational seminar, I spoke to them about starting a support group for local AS sufferers. Thanks to SAA, I have been able to field questions from people with AS, get people together to talk about their challenges and successes, and hook people up with rheumatologists who specialize in AS.

When SAA needed funding, I was there for them, just as they were there for me when I needed answers to my questions about AS. I’ve been fortunate, and have done well in life (I was an independent insurance agent who wound up owning my own agency). I’ve always contributed financially to worthwhile causes, but I decided
to join the Quest Legacy Society and leave money in my will for the Spondylitis Association because of the work they do to help AS patients and educate those who don’t know much about the disease. It is unimaginable to me that one might lack a sense of responsibility for the problems people face with this disease. As I said, I’ve been very fortunate; I know where I fall economically, and I can’t imagine not giving back.

My legacy gift to SAA is my way of saying “Thank You.” Thank you – in the words of SAA mission statement – for being a “leader in the quest to cure ankylosing spondylitis” and thank you for “empowering those affected to live life to its fullest.”

For more than 40 years, I have lived with ankylosing spondylitis. My body has been through a lot, but I have been lucky to have stayed as active as I have for as long as I have. I am making this legacy gift so that doctors and researchers can learn more about this disease and develop better treatments for people in the future. I am making this legacy gift so that others will not experience the disease as I have, but will live with the knowledge that a cure is on the way.

Become a Member of the Quest Legacy Society

Your gift, large or small, can make a difference

The Quest Legacy Society was established to recognize and honor the generosity of those individuals who have kindly remembered the Spondylitis Association of America (SAA) in their estate plans. If you have named SAA in your estate, please let us know so that we may welcome you as a member of the Quest Legacy Society.

As a Quest Legacy Society member, you will play a leading role in helping the Spondylitis Association continue the important work that is changing thousands of people’s lives for the better. Planned gifts, large or small, go a long way to providing SAA with the resources needed to stay in the forefront of spondylitis research and continue to provide vital programs and services for future generations affected by the disease.

As a member, you will also receive special updates on SAA program services and be listed as a Quest Legacy Society member on SAA’s website and in the Annual Report. Much more importantly, you will gain the satisfaction of knowing that future generations affected by spondylitis will have the resources necessary to better manage the disease.

For more information on becoming a member of the Quest Legacy Society, and how planned giving can work for you, please go to www.spondylitis.org/quest or contact Susan L. Jones, Director of Development and Planned Giving at 800-777-8189, ext. 231 or by email at susan.jones@spondylitis.org.
What do spondylitis and Bach’s Cello Suites have in common? Not much, really, except for an innovative, new fundraising initiative, called “Bach to Health.”

“Bach to Health” combines the twin talents of Eric Roter, M.D., an emergency room physician at Kaiser Permanente in Cleveland and a Juilliard trained cellist, to help raise money for some of the country’s top-rated healthcare charities, including the Spondylitis Association of America. Dr. Roter created 36 videos using the movements of Johannes Sebastian Bach’s masterpiece Cello Suites and dedicated each one to a leading nonprofit healthcare organization.

“For years,” says Dr. Roter, “I tried to figure out ways to combine my dual talents as a physician and musician. With the advent of high-speed Internet and streaming video, I realized that I could put it all together - music, medical education and philanthropy – by videotaping myself playing the cello and then embedding educational text and a donation link within each video. It all came together at once, like the Big Bang.”

When Dr. Roter was a student at Juilliard in Manhattan, he sometimes performed in trios and quartets on the sidewalks of the City, using the donations of passersby to help pay for food and living expenses. “What if,” thought the doc, “I created a way where people could still enjoy my playing, and yet this time, have their donations go directly to a worthy medical cause?”

Each video of the Cello Suites is set against a background of familiar street scenes of Manhattan, highlights facts about a disease, and provides a link to make tax-deductible donations. The videos can be viewed on YouTube or through Dr. Roter’s website www.bachtohealth.org.
The charities include the American Liver Foundation, the ALS Association (Lou Gehrig’s disease), the Michael J. Fox Foundation (Parkinson’s disease), the Arthritis Foundation, the Asthma & Allergy Foundation, and SAA, among others. All of the charities have national visibility and are highly rated by the American Institute of Philanthropy and Charity Navigator. “I wanted to use charities whose patients I often treat in emergency situations in the ER,” says Dr. Roter, “and ones whose donations are used wisely and ethically.”

He chose SAA as one of the charities in part because he has a special interest in rheumatic diseases -- his wife is a board-certified rheumatologist. He dedicated Bach’s Suite No. 4: Sarabande to SAA. “The 4th’s Sarabande reflects spondylitis in that its tempo is somewhat slow and harmonic and the rhythmic content is rigid, but it has a bright inner beauty which shines through. It is exceedingly difficult to perform on the cello.”

Laurie Savage, SAA’s Executive Director and a pianist herself, told ABC National News that Dr. Roter’s selection of SAA as a participating charity was “music to my ears.” ABC recently ran a feature on “Bach To Health”, which also highlighted SAA (a link is found on the Bach to Health website). Ms. Savage says the exposure through “Bach to Health” will help create awareness about a disease that most people know little about.

Dr. Roter was delighted that Ms. Savage is also a musician. “One of my hopes early on,” he says, “was that some of the charities might have staff or board members who would get what I was doing – making a connection between the greatest art and the greatest charities. Both musician and charity strive to do the best they can for a much greater cause. Laurie made the connection immediately.”

Dr. Roter states that “Bach to Health” is just the beginning of his work to bring donations and attention to his charities. “There is so much more that can be done using music, for it is indeed the universal language and human illness and suffering extends far beyond the borders of any one country.”

To view the videos and donate to SAA, please visit www.bachtohealth.org, click on The Charities & Videos, and choose Suite #4: Sarabande.
Richard Feingold, Esq. recently spoke with Melissa Velez Coelho, SAA’s Director of Program Services, about Social Security Disability Benefits. Below is a small excerpt from this podcast. To listen to the entire audio interview, log in to the Member Only Area of spondylitis.org.

**MVC:** What are Social Security disability benefits?

**Rich Feingold, Esq.:** These are benefits that are paid by the federal government. The program is administered by the Social Security Administration (SSA) which provides benefits for people who are disabled or blind.

There are two different kinds of Social Security benefit programs for people who are disabled. There are Disability Insurance Benefits, which are based upon wages earned and FICA taxes paid. Then there are SSI benefits, Supplemental Security Income benefits, which are benefits for people who either have not earned enough work credits through paying FICA taxes or who have earned enough credits, but who now meet the asset and income limitations required by the SSI program.

**MVC:** How does a person prove they are disabled?

**Rich Feingold, Esq.:** Basically it’s the same for both programs. The basic definition of disability is you have to have a medically determinable physical or mental impairment that has lasted, or is expected to last, a continuous period of at least one year that prevents you from doing any work at all. SSA has a five-step process for adults to determine whether or not they are disabled.

**MVC:** What is that process?

**Rich Feingold, Esq.:** For an adult claim, the first question is “Are you working?” SSA doesn’t really use the word working. They use a legal term, “Substantial Gainful Activity”, work that you do for pay whether you’re working for yourself or working for someone else. For a non-blind individual, if you earn over $1,000.00 a month of gross income (before taxes, for the year 2010), you are considered to be working. If you are working and making too much money, SSA will say, “You’re not disabled because you’re working, and part of being disabled means you are unable to work.”

The next thing SSA will ask is “Do you have a severe impairment?” To prove a severe impairment, it has to at least minimally affect your ability to perform work-related activities such as standing, sitting or walking, or concentrating and interacting with other people. If you have ankylosing spondylitis, for example, and you have a lot of pain in your back and you can’t stand all day or walk all day because of fusing of your SI joints, then that would constitute a severe impairment.

It can also apply to a mental impairment, for example, depression. You can’t handle constant interaction with the public. That could be considered to be a severe mental impairment, so that would meet step two of the process.

The third step is to take a look at your impairments. Does it meet SSA’s listing for ankylosing spondylitis? Listings are basically medical criteria that SSA has codified into their regulations to determine whether or not your impairment is sufficiently limiting in itself to be considered disabling.

In SSA’s listing for ankylosing spondylitis, not only do you have to have the diagnosis of ankylosing spondylitis, but, for example, you would have fixation of the spine at 45 degrees or more flexion from the vertical position. It would either be the dorsolumbar spine, or the cervical spine. If you have what they call the fixation at that degree, then you could meet the listing and be entitled to benefits.
Another way you can meet it is if you have, for example, 30-45 degree fixation of the spine and, in addition, you have two or more organ body systems at least involved to a moderate degree of severity. As you well know, with ankylosing spondylitis, oftentimes there are other symptoms and body systems involved in addition to severe fatigue, etc. SSA says if you don’t have 45 degree fixation, but you have two other body systems involved, at least to a moderate degree, you could also meet the listing.

But let’s say you don’t meet the specific criteria in the listing. SSA would then say, “Okay, you don’t meet the listing but let’s go on to steps four and five. Can you do your past relevant work?” Past relevant work means work you have done within the past 15 years. They look at the physical and mental demands of that work. Do you have to walk all day? How much do you have to lift? How much do you have to carry? How much do you have to push or pull? Maybe you’ve been a truck driver. You might have to operate a gear shift or maybe operate foot controls or pedals. They also look at the mental demands of your past work.

Then they look at how you’re currently doing physically and mentally and they say, “Well, based on the fact that now the most you can do is sit, you can’t stand and walk for more than two hours out of the day. All your past work required you to stand and walk at least four or six hours. You can’t do that. Mentally, you used to do skilled work. Now, because of depression or pain your concentration is diminished. You can’t do any of that past work. You’re reduced to a semiskilled job or an unskilled job.”

If you can’t do any of your past relevant work, the last question is, “Is there any other job you can do in the local or national economy given your age, your education, your past work experience, any transferable skills and your residual functional capacity? What can you still do?” SSA has to prove there are other jobs you could do given those limitations. If they prove there is another job you can do given all the legal requirements, then you’re not disabled. If there are no other jobs that exist in significant numbers, then you are disabled and should be awarded benefits.

To listen to the remainder of the podcast including information about working with your physician and gathering medical evidence to prove disability, log in to the Member Area of spondylitis.org.

About Richard Feingold, Esq.

RICHARD I. FEINGOLD is a nationally respected Social Security Disability attorney and founder of Richard I. Feingold & Associates, P.C. in Chicago, Illinois. He has practiced law for 23 years and represents clients nationwide. He currently answers questions on SAA’s message boards in the forum entitled Questions About USA Social Security Disability Benefits.

Disclaimer: Mr. Feingold’s comments during the interview are offered as a public service, are general in nature and do not constitute legal advice for any specific legal situation or problem that you may have. Please be advised that no attorney-client relationship is created between Richard Feingold and those who listen to the podcast or review this article. If you have a legal problem, you should contact an attorney to personally discuss the matter.
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With most people today watching their money, you should know that for just pennies a day, your membership gives you access to a wide array of resources that you won’t find anywhere else.

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We’ve put the most asked for resources in one convenient place. SAA’s Member Resource Directory includes sections on Disability and Work Related Issues, Financial Help and Assistance, Health Insurance, Medication Assistance and Support Resources.

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You can also download the 32-page eBook, Your Guide To Living With Ankylosing Spondylitis and any of SAA’s informative brochures.

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The benefits of membership are many. Make sure you’re getting everything your membership has to offer!
If you’ve visited spondylitis.org recently, you may have noticed that we have a different look. But, did you know that SAA’s website is the single largest resource for all things spondylitis?

- Whether you’re newly diagnosed or have lived with spondylitis for decades, you’ll find up-to-date information on symptoms, diagnosis, complications, medications, traditional treatments as well as alternative therapies – all in one convenient place.

- Our News section is updated regularly with the latest on research, treatment advances, medical trends and other information of interest to the spondylitis community.

- You can sign up for our free eSUN: the electronic Spondylitis Update Newsletter to receive monthly updates of upcoming events, news, support programs and more!

- Connect with others on SAA’s interactive message boards. You’ll find an active community of people who always take the time to answer a question, provide support or just make you laugh when you’re having a tough day.

- Visit the Advocacy section to find out how you can help influence the lawmakers who makes decisions on issues of importance to the spondylitis community.

- Update your contact information using our convenient online form so you don’t miss out on any of our valuable program services. Update your info today in the member area at: www.spondylitis.org/members

- Share the page you’re looking at on your favorite social networking sites to help spread awareness.

- Subscribe to our RSS feed so you can be alerted whenever updates are made to the website.

- You’ll also find many ways to help support the only organization that focuses all of its resources on changing the landscape of spondylitis for the better. Whether you join, renew, donate a vehicle, start a support group, make a memory/honor gift or would like information about including SAA in your will, the new spondylitis.org is the place to start!
SAA acknowledges the passing of several longtime friends...

Rob Williams

Rob Williams, 38, beloved son of Dr. Dave and Jan Williams, and our dear friend, lost his long battle with bipolar depression which he had kept at bay so successfully for almost 20 years.

Born October 7, 1971 in Nashville, Tennessee, Rob moved to California with his parents when he was nine months old and always considered himself a native. He attended Laguna Blanca in Santa Barbara, The Thacher School in Ojai and Wesleyan University in Connecticut, where he received a B.A. with Honors in the College of Social Studies, a selective program combining history, philosophy, government and economics.

Always a gifted athlete as well as an excellent student, Rob participated in many sports. Individual sports including tennis, fencing and golf, as well as team sports like baseball, basketball and his favorites, soccer and lacrosse. When he was a freshman in college the intermittent back and leg pain which he had experienced from the age of ten became quite severe and he was diagnosed as having ankylosing spondylitis (AS).

In October, 2001, Rob, with his friend Sandra Uesugi, undertook a bike ride across America, from Washington D.C. to Santa Barbara, CA to raise funds for and awareness of AS. He spoke at medical schools along the route hoping to make the young doctors more aware of the symptoms in order to promote earlier diagnosis.

Rob was our champion and he will be sorely missed. We would like to thank Dr. Dave and Jan Williams for their generosity in their time of great loss. SAA was the recipient of many memorial gifts in Rob’s memory.

Ken Genser

Former Santa Monica Mayor, Ken Genser, who had severe AS, was active in SAA during its formative years. Most significantly, in 1995, he arranged a meeting with Congressman Henry Waxman, an influential leader of health issues in Congress who was chair of the Energy and Commerce Subcommittee on Health and the Environment at the time. As a result of that meeting, Congressman Waxman sent a letter to NIAMS requesting a report on the projects and funding of AS and spondyloarthritis (practically non-existent at the time). This alerted NIAMS that there was significant interest in the disease, and therefore helped pave the way for SAA-initiated genetic research in ankylosing spondylitis.

Marcy Kallison

Marcy Kallison, the father of SAA’s founder, Jane Bruckel, was a very generous man who supported many charities. Because of his pride in his daughter’s accomplishments, he had a special place in his heart for SAA. He loved reading Spondylitis Plus and was always impressed by the progress made by the organization.

We are very grateful for his many years of support and for his generous bequest.
SAA-Sponsored Educational Support Groups

The people listed below have volunteered to lead support groups across the US. If you’d like to find out more about support groups and online meetings, visit our website at: http://www.spondylitis.org/patient_resources/

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Email us at reservations@spondylitis.org or call Elin Aslanyan toll free at 1-800-777-8189 x222 for information.