

SPONDYLITIS PLUS

fall 2006



**SUFFERING KEY TO
COMPASSION?**

SAA'S WALK IN THE PARK

**REMEMBERING A VERY
SPECIAL FRIEND**

SPONDYLITIS SUPPORT GROUPS

**THE NIH FUNDS
A.S. GENETIC STUDY**

SPONDYLITIS ASSOCIATION OF AMERICA

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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

Published four times a year

Laurie M. Savage, Editor-in-Chief
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Design by Cause Communications
Printing by PMF Productions, Inc.

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you seek the counsel of a physician
before initiating any treatment for
spondylitis. Annual subscriptions are
available with a membership.*

UPFRONT



Dear friends, the good news is in!

The National Institutes of Health once again has demonstrated its support of AS Genetic Research by funding the next phase of this important endeavor. A grant of \$5.25 million has been awarded to Dr. John D. Reveille, University of TX, Houston, beginning August 1, 2006, and ending June 30, 2011.

The overall responsibility for the study will continue under the expert guidance of Dr. Reveille, Principal Investigator, and the SAA will continue to play a significant role in patient recruitment and administration. As Co-principal Investigator for the administrative core of this study, I look forward to reporting the advances achieved over the next 5 years.

The effectiveness of the SAA in re-igniting ankylosing spondylitis research in the U.S. would not have been possible without the collaborative relationships with Dr. John Reveille and his colleagues, without the support of Dr. Stephen Katz and Dr. Susana Sztein at the NIH, without the work of the SAA Board and staff, and, of course, without the support of you, our members.

Results are strong drivers of motivation. They support our purpose, and increase the likelihood of long-term success. Though it is up to each of us to make success happen, we all must work together to achieve truly significant outcomes.

To date, thanks to 400 very special families who have participated in the AS Family Genetic Project, we have reached a major milestone in uncovering regions on seven chromosomes that suggest susceptibility to AS. We have much more work to accomplish. Please help us to achieve our goals so that together we can end this disease and its impact on the lives of so many.

We are tremendously grateful to Dr. Reveille for his continued commitment to the cause, and we thank him and his worldwide team for all of their efforts.

ASSOCIATE EXECUTIVE DIRECTOR

For a description of the study, please visit the NIH CRISP database query page at http://crisp.cit.nih.gov/crisp/crisp_lib.query and type into the PI search field Reveille. The project title of the grant is Genetics and Ankylosing Spondylitis (AS) Pathogenesis.

To find out about participating in the study, please call the SAA at (818) 981-1616 x 224 or email info@asresearch.org



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From our Message Board

Since retiring a few months ago due to my AS progression, it's given me a lot of time to reflect on the past and some of the glory days so to speak. I did a lot of things that weren't very smart to do physically with the diagnosis of AS in which I was diagnosed when I was around 20 or so. I raced snowmobiles in both outlaw and enduro (off-road) events for 12 years, as well ATV ice racing in which I won a national title in the mid nineties. I'm truly glad to this day I was able to enjoy something that I loved to do so much despite my early diagnosis of AS. One thing this disease can't take away from us is our memories and joys of the past.

Since then, I've had the joy of watching my little 4-year-old guy zooming around our yard with his power wheels four-wheeler. I've never coached him about riding other than safety. I grin ear to ear watching him leaning forward gassing the throttle shifting his weight back and forth its like he is a natural born little racer! I'm looking forward to many more proud smiles!

Do you find more substance in life since AS? Is it perhaps because it slows us down to see life in a bigger way? I find that many of us may be limited in some ways by disease, but there are many who have moved on only to become more creative, compassionate, and loving in their life's despite AS!

TERRY G. STEPHENS
Breckenridge, Michigan

I have also changed my life a great deal since being afflicted with this disease, but

it is not all bad. While I used to fill my spare time with athletics: randonee skiing (ski mountaineering), water-skiing, softball, scuba diving, etc.; I now spend my time studying hypnotherapy and painting fine art.

I miss the achievements of the past (competitive sports), but I now enjoy nurturing my creative side and more of the quiet things I used to complain that I never had time for. I view this as a new and different chapter in my life and try to be positive and philosophical about it!

Something too, is that I have found much comfort and growth in the time I invest with family, friends, and support groups. Particularly with the support groups, I find that I both receive and contribute in life altering ways that make my life rich. I find now that although my life is limited in many ordinary ways, I enjoy a deeper sense of the things that really matter.

My life is different, to be sure, but in many ways it is better!

BARBARA GRONDAL
Everett, WA

I remember one of the surprising things I did after being diagnosed, was briefly returning to acting. I had given it up as a career choice after being diagnosed, and had decided to try to become a playwright, but, around 1989, after I was totally fused, a friend called and told me that the lead in his play had dropped out and would I take the part. I was very leery, especially since the play opened in a week. But, I allowed myself to be talked into it. Since I could no longer

turn my head, I had to figure out how to "place myself" on the stage, so that I could relate to the other actors and yet also be seen by the audience. It was a rough week, and way too many lines to memorize, but somehow, we did it. It went over well, and most people didn't obsess on my inability to turn my head. They were aware of it, but didn't let it distract them from the play.

That performance introduced me to an arts festival that would, over the next five years, produce 4 of my plays, most of which were one person shows that I also performed in. I don't think I could ever do that now, but it was nice to have that opportunity and then to have such success come from it.

MICHAEL SMITH
New York, NY

EDITORS NOTE: *This subject was recently introduced on the Message Boards on the SAA web site. Visit this online community and forum at www.spondylitis.org.*

FORUM CONTINUES NEXT PAGE

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

Thank you for your article, "AS Diagnosis in Children Can be Difficult to Obtain," on our grandson, Brian Annett. Witnessing this whole saga Brian and his parents went through was absolutely horrific for them as well as Brian's two older siblings, the older of whom has been diagnosed for several years now with psoriatic spondylitis. Having to sit on the sidelines and watch all this was unbelievably hard on us as grandparents as well as—parents. We wanted more than anything to be able to help solve this dilemma—love, prayers, emotional support were all we could give and that we gave and still give with all our hearts.

I hope by your publishing our story other parents can be encouraged to pursue needed help when symptoms warrant it, and to not allow misdiagnoses and mistreatment overrule a real physical need.

Brian is coping with everything just fine now—his wonderful, wacky sense of humor has returned, his grades have picked back up; and, most of all, he still dreams of hitting Olympic qualifying times in his swimming and of having a chance to go to the Beijing Olympics in 2008 representing the United States. His doctors, coaches, family, teammates, and friends are supporting and working with him all the way to help him attain his dream! Thanks for telling his story!

ANN MCCRAW
Lake Forest, CA

Our son was diagnosed with AS about 18 months ago. To learn more about the disease and to encourage him to take a greater role in self-care, I subscribed to your magazine and logged on to the website.

Our son won't read the newsletter; I only glance through it once in a while; and I don't go to the website. Why? Because we are looking for information and success (or at least, healthy self-management) stories.

Reading the AS news magazine is like getting the bad news again—and again—and again. Developing a hopeful, upbeat outlook is not about denying that there is a problem. However, your magazine comes across to us like a victim's advocacy program with emphasis on victim-hood and conventional medicine. We live in a small town and are stuck with conventionality, which includes a rheumatologist who coupled the diagnosis

with a clinical prediction of a painful and extremely limited life. Sort of like reading your magazine (which he recommended).

I recognize that you do include stories about coping strategies. "My Story" in the May/June 06 issue is an example of the negative focus: The writer tells us a few things he has learned along the way, but only after highlighting details of his limited and painful existence. May I suggest that you counter-balance these kinds of stories with straightforward information on treatments.

Our son does experience constant pain and limited mobility. However, it is his mental attitude which will determine how he responds to this. We refuse to permit the limited vision of others to create our reality.

It is not my intention to accuse you of being "wrong." I do recognize that some people like this support-group-you're-not-in-this-alone mentality. When we find a resource that takes the stance of "ok-so-you-have-a-bad-disease-let's-get-on-with-life" approach, we'll subscribe. Thank you for permitting me the opportunity to articulate my thoughts.

ANN LARROW
Chambersburg, PA

Just wanted to let you know that Orange County teens with A.S. had its first support group meeting this past Sunday, and it went great!

Here are the highlights of our meeting: The first-ever support group for Orange County, CA teens with Ankylosing Spondylitis had its kickoff meeting in August 2006. Co-founders Tyler Walker and Katlin Poladian organized the event and set the agenda. The group was named Teen Athletes with Spondylitis.

"We wanted the group name to include the word 'athletes,'" said Katlin. "Each of us is involved in high school and club sports, ranging from basketball to swimming and water polo."

The teen support group currently has members from four Orange County high schools, including Tesoro, San Clemente, Mission Viejo and Santa Margarita.

"We're each active, athletic, funny and intel-

ligent," said Tyler. "We just happen to be living with, and dealing with, a lot of pain."

The group was scheduled to meet for an hour, but members were still sipping Starbucks lattés and frappaccinos three hours later.

"We talked about everything from how we deal with our symptoms, to movies, sports and school," said Tyler. "It seems that teens with A.S. in the O.C. have a lot in common."

The next meeting for teens is scheduled for Sunday, September 10th at 2:00 PM. Teens ranging in age from 13 to 19 are welcome. Please contact Tyler Walker at WalkerRSM@aol.com for more details.

TYLER WALKER
Mission Viejo, CA

How inspiring to see teen athletes with spondylitis on the cover of the May/June edition of Spondylitis Plus. I was diagnosed with ankylosing spondylitis three years ago at the age of 13 and it's been tough, but it lifts my spirits to read about other teens who are making the most of what they have, in spite of their illness.

It was interesting to hear about their difficulties with diagnosis and the ongoing struggles these young men face in everyday life as a result of spondylitis; but also their successes and triumphs, and how they stay active in spite of this disease.

Thank you for illustrating the fact that spondylitis also affects the young.

MEGAN
via email

Our many thanks for sending along copies of the new spondylitis brochures – they are absolutely terrific! I'm copying several people from the AF Marketing & Communications area to see how we can best help inform people with spondylitis about their availability. We very much recognize the importance of partnerships, and are anxious to make certain people know about the Spondylitis Association of America.

JOHN H. KLIPPEL, MD
President & CEO
Arthritis Foundation
National Office

A REPRINT FROM JEMS. BY BRYAN BLEDSOE, D.O.

Ankylosing Spondylitis Patients Need Special Care



Bryan Bledsoe, D.O.

In a small town in Indiana a man collapses, and EMS is summoned. When paramedics arrive, they find the man in cardiac arrest. So, based on their education and experience, they begin resuscitative measures. Per protocol, they elect to place an endotracheal (ET) tube. During the process of intubation, they extend the head to properly visualize the airway. Unfortunately, they hear a “crack”. The patient’s cervical spine is fractured and the spinal cord injured. The paramedics did not do anything wrong; they followed established protocols. But the patient suffered from a condition called ankylosing spondylitis (AS), a condition that requires care modifications.

An estimated 500,000 people in the United States have AS, a form of inflammatory arthritis that primarily affects the spine. The disease causes inflammation of the joints between the vertebrae of the spine and the sacroiliac joints in the pelvis. It can also cause inflammation and pain in other parts of the body. As the condition worsens and the inflammation persists, new bone forms as a part of the healing process. The bone may grow from the edge of the vertebra across the disc space between two vertebra, resulting in a bony bridge. This may occur throughout the spine so that the spine may become stiff and inflexible, effectively fusing the spine. On spinal X-rays, this phenomenon is referred to as bamboo spine. This fusion can also affect the rib cage, restricting lung capacity and function.

As the disease progresses, the spine can become fused into a single unit incapable of flexion, extension or lateral movement. Usually, the fusion progresses with the spine assuming a flexed position and the patient forced to walk bent over.

EMS providers called to care for a victim of AS must remember that their patient’s spine is inflexible and cannot be moved. Further, the fused spine can be extremely fragile and subject to fracture with resultant spinal cord injury. Numerous EMS techniques must be

modified to accommodate patients with AS. These include airway management techniques, splinting techniques and transport considerations. Because most AS patients have spinal flexion, it’s important to adequately pad

underneath the patient’s head, neck and upper back with a pillow or pillows. Likewise, airway management techniques must be applied without extending the neck. Airway devices that do not require visualization (e.g. CombiTube, LMA) should be considered instead of ET intubation, with cricothyrotomy used as a last resort.

Although AS is not common, improper EMS care of patients with the disease can be devastating. Learn to identify the signs and symptoms of AS, and protect the spine accordingly.

Learn more at online at:
www.spondylitis.org/about/main.aspx.



YOU NEED TO KNOW

WHEN EVER POSSIBLE, PLEASE ALERT MEDICAL PERSONNEL OF YOUR CONDITION AS A PATIENT WITH SPONDYLITIS SO YOU GET THE PROPER MEDICAL ATTENTION, REGARDLESS IF THE SITUATION IS A.S. RELATED.

SAA acknowledges with gratitude Dr. Bledsoe’s efforts, on our behalf, in writing this article. It was published in the Journal of Emergency Medical Services in July 2006.

SoundBites in Rheumatology

Disease and Psychological Status in Ankylosing Spondylitis

Authors: J. Martindale, J. Smith, C.J. Sutton, D. Grennan, L. Goodacre and J. A. Goodacre.

Ref. Rheumatology Advance Access published April 4, 2006

Objectives: In this study, the researchers set out with two main objectives. To describe the association between disease and psychological status in AS, employing AS-specific tools and questionnaires, and then, to determine whether the assumptions generated by the study would remain stable over time.

Method: In this study, a total of 110 patients with AS were assessed at six-month intervals, up to four times, using tools to measure disease activity.

Results: Eighty-nine participants completed all four assessments. The researchers were able to determine that those patients who were clinically anxious or depressed had significantly worse clinical outcome in disease activity and ability to function. The mean scores for disease, psychological and health status proved to be clinically stable over time.

Conclusion: Disease status scores in AS correlated significantly with anxiety, depression, general well-being (internality), and health status. It was concluded that these findings have important potential applications in the management of AS and may even play a role in identifying candidate patients for biological therapies.

Bone Density, Ultrasound Measurement and Body Composition in Early Ankylosing Spondylitis

Authors: E. Toussiro, F. Michel and D. Wendling

Ref. Rheumatology 20001;40:882-888

Objectives: Patients with AS were evaluated for bone mineral density (BMD) using two different types of measurement devices: dual-energy X-ray absorptiometry (DEXA); and quantitative ultrasound (QUS).

Method: Seventy-one patients with AS were compared to seventy-

one sex and age-matched controls. Each person underwent an extensive physical exam, which included BMD of the lumbar spine and femoral neck, total body measurements were performed, including bone mineral content (BMC) of the whole body, fat and lean masses. Broadband ultrasound (BUA) was used to measure stiffness of various aspects of the skeleton, and the heel bone (calcaneus) was examined using an Achilles ultrasound device.

Results: According to the researchers, the patients showed significant differences and lower BMD of the lower spine, femoral neck and total body when compared to unaffected people in the study. Fat and lean mass turned out to be just about the same in both groups.

Conclusion: The results of this study confirmed that AS patients have decreased BMD values, reflecting a generalized bone loss. On the contrary, soft tissue does not seem to be impacted by the disease. The study did not support the use of QUS as an adjunct tool to DEXA in measuring bone loss in people with AS.

Childhood-Onset Arthritis Linked to Increased Risk of Fracture Ann Rheum Dis 2006;65:1074-1079

According to a recent report from Reuters Health, people with childhood onset arthritis have a significantly increased risk of bone fracture in childhood, adolescence and it has been suggested in adulthood.

Dr. Jon Michael Burnham and colleagues, Children's Hospital, Philadelphia, Penn., identified 1,939 individuals who had been diagnosed with childhood onset arthritis, between the ages of one and nineteen years of age.

The researchers found that there was a significantly higher incidence of bone fracture, particularly in the arms and legs of the patients with juvenile onset of rheumatic disease.

From the results of this study, Dr. Burnham and his colleagues deduced that it is critical for children with arthritis to be monitored thoroughly, and for the arthritis to be well controlled. They also suggested that the immobility associated with active arthritis may exacerbate the already known recognized complication of osteoporosis related to childhood arthritis.

“A.S. HAS BEEN A BLESSING”

Colorado Man Sees Suffering as Key to His Compassion For Others

Ron Ansay, 73, is an ordained deacon in the Roman Catholic Church with more than six decades of charitable work behind him who has had ankylosing spondylitis since he was about 12 years of age. The charity work and the disease started about the same time. He tells *Spondylitis Plus*, “In a sense, AS has been a blessing in my life these past sixty years as it has made me more compassionate to others’ suffering of any kind.”

Ron was given a definitive diagnosis for his disease at the age of 21 at the Mayo Clinic, but only after a decade of suffering intense pain. “In my youth, I would lower myself out of bed and onto the floor, using my elbows to crawl; my dad couldn’t accept the fact that his son had problems so he would scream and yell and holler at me.”

Scoffing doctors were the worst

His father, a victim of the times, and upon doctor’s advice, figured that hard work would make his frail son with the “growing pains” into a man, so Ron was forced to work in the family linen supply and laundry facility where it was continually steamy, dank and damp. The teen was oftentimes diagnosed with rheumatological disorders, such as osteochondritis and osteomyelitis and he was forced to wear cumbersome braces on his legs for a year, in addition to using crutches.

He said that when doctors scoffed at his pain, that was “the worst” because it hurt his spirit. Still, as a young boy in Milwaukee, he would go to the orphanage and play the accordion for the children to entertain them. “Even with the pain, I was still better off than they were,” he says now.

In 1981, while attending his father’s funeral, Ron saw two cousins that he had never met before. He said they were “heavy set and walking with crutches.” He asked them about their health and was told that they both had AS.

She still married me

He married the former Dolly Pohs of Denver in 1955, a woman he calls his “fabulous partner and caretaker through the years.” “Knowing I had the disease and knowing that the Mayo Clinic said I could be in a wheelchair, she still married me; she doesn’t baby me, but she understands the depth of the suffering and she’s seen me through 20-something surgeries, which is the reason I’m doing so well right now.” Ron, a realtor with the Kentwood Company, has had his right hip replaced twice; ditto his right shoulder.

The couple has seven children, 30 grandchildren and four great-grandchildren and all are healthy at this point in time; only Ron’s sister’s son has AS.

This was their life; they had no other place to run

Ron has given back to the community for years, working to improve society and to promote justice, an enduring theme of his life. In the 1960s and 1970s, he got involved in the Chicano movement, or *movimiento*, that highlighted the rights of farm workers.

One summer vacation, he took his brood of seven kids and his wife and they worked in the fields for a short time picking lettuce. He remembers an aerial plane dropping pesticides on the plants and he said everyone ran from the fields for shelter. His family ran to their parked vehicle where they stayed till the cloud of parathion, a broad-spectrum insecticide, dissipated. Ron says: “The valuable lesson for my children was that the farm workers had no other place to go; this was their life. All of these experiences gave them more of a sense of social justice.”



Ron and Dolly celebrate 50th wedding anniversary in Paris .

Columbine is well etched

Burned into his psyche, is April 20, 1999, the day two teenage students at Columbine High School went on a shooting spree that left 12 fellow students dead and a teacher

as well, and 24 others wounded before the disturbed pair of youths committed suicide.

“Columbine is well etched,” Ron remembers, his voice dropping into barely a whisper. “The Archdiocese of Denver called me and asked me to dress in my clerics (roman collar) and go to Littleton Hospital to be of assistance. Most of the bereaved families were in deep shock so I merely walked the halls and stopped to talk and offer any assistance I could; it was one of the more difficult things I have done in my life.”

Still thankful after all these years

But then, he moves on from his heavy heart at the memory of the massacre, and again says he is “thankful for his illness.”

Ron states: “I mean that with all my heart. I thank God for the illness every day. I do everything I can to try and be healthy: drugs—Remicade infusions; I see my wonderful rheumatologist, David Korman, M.D. with offices in Rose Medical Center, Denver regularly for check-ups; I religiously take care of things although the pain is still there. You either feel sorry for yourself and people won’t want to be around you or you can accept it—and I’ve accepted it from the time I was a young man.”

ANNUAL WALK KICKS UP SUPPORT FO



ON MAY 20TH, HUNDREDS OF ENTHUSIASTIC MEN, WOMEN, CHILDREN and even man's best friends took part in this annual event to raise funds to facilitate spondylitis research and to improve public awareness of AS and related diseases. Sixth-year Chairperson and Gold Sponsor **Raquel Magro**, who was also this year's top individual fundraiser, once again took the lead in ensuring a successful and enjoyable day in the park at Lake Balboa in Encino, California.

Earl Broidy, RPh, owner of Panorama Compounding Pharmacy, was honored for his service to the SAA Board of Directors from 1997 to 2005. SAA is grateful to Earl for his years of dedicated service to the foundation.

SAA would like to thank the members of the Walk Committee, our sponsors, benefactors, volunteers—and all those who participated by sponsoring walk teams via the web—for making the day such an enjoyable one for all. We hope to see you all next year when we'll do it all over again.



R RESEARCH AND PUBLIC AWARENESS



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**Special Thanks to Konica Minolta-
Printing 2006 Walk Brochure/ Save
the Date Card**

Remembering My Very Special Friend

Sherry Fox 1942-2006



Sandy Ingraham and Sherry Fox



The first I time I heard of Ankylosing Spondylitis, I became acquainted with an extremely special person. Sherry Fox and I met at our church and became fast friends. She was diagnosed with AS when she was in her early twenties, however, the disease actually started when she was 17. As our friendship grew, I asked her a lot of questions about the disease that plagued her for some 40 plus years. I read her *Spondylitis Plus* magazines and decided to join the Spondylitis Association of America. Not only would I help support SAA but I also wanted to be informed with current information regarding AS so I could be the most effective best friend to Sherry.

I was so excited when I saw her name in the magazine listed under the Athletes Against AS Advisory Board. She was on the Board for many years, and was recently contacted by SAA encouraging her to stay on. She wasn't sure if she qualified to do that anymore because of recent setbacks. She shared with me that the person who spoke with her was very kind and such an encouragement as well and she suggested she remain on the board.

The most predominate quality about Sherry was her love and concern for those around her. She didn't focus on herself or her AS.

Sherry was involved in many sports through the years and didn't let AS keep her from enjoying such activities as golfing, ice skating, swimming, downhill skiing, bowling, basketball, baseball, art and painting, and more recently, high-performance driving. By the time we met, Sherry had just retired from the high-performance driving, I think to the relief of her driver friends. I have heard over and over how she cleaned their clocks at the track. She possessed a rare talent for driving and was exceptional on the track. Although retired from the track, Sherry continued to be active on a daily basis. She was supporting her husband and his extremely active business, caring for her elderly mom and keeping up with of the grandchildren. Her son and daughter each have 3 children, which include two sets of twins!

The most predominate quality about Sherry was her love and concern for those around her. She didn't focus on herself or her AS. She always wanted to know how you were doing, offering encouragement and help in any way she could. Her focus was on others just about all of the time. It didn't mean she wasn't proactive in her health and her AS. She was diligent about that. Everyday she exercised in her hot tub, took vitamins, ate healthy and used prescription strength NSAIDs to help keep her pain under control. All of these together helped her live life to the fullest. Her drive and enthusiasm for life was her strongest ally. Although she dealt with pain everyday, she pushed through it and did activities on the spur of the moment or when the opportunity arose. Her AS was acute right from the onset of her symptoms as a teenager but she didn't let it keep her from getting the most out of life. She always made sure she had another focus or activity to get involved in if she had to curtail one due to physical limitations. As she got older, she did have to cut back on the more vigorous activities (downhill skiing, bowling, etc.).

For the last several years we enjoyed many activities together. We packed a lot in mainly because of Sherry's drive to stay active and to just "go for it" with every opportunity. Some of these activities included swimming, boating, fishing, vacationing together, and playing music together in church, a passion we both shared.

Sherry died not long ago from cancer and she is missed so much by those who were touched by her life. She was such an inspiration. Her relationship with God made her life complete and fulfilling. Her faith was the most compelling testimony to me personally. I learned so much about living a joyful life and having faith in all circumstances from my best friend, no matter how dire things seemed!

I recently had the opportunity to share my *Spondylitis Plus* magazines and information regarding SAA, on two separate occasions, with families affected by AS. To be able to share that information with them, I knew, was a direct result of my friendship with Sherry, a friendship that changed my life forever.

– Sandy Ingraham

ALL THROUGHOUT HER LIFE, Sherry had always enjoyed sports and needed a physical outlet. The lure of high-performance driving was one she couldn't resist, and she wasn't about to let AS stop her. In our Winter 2000 edition of *Spondylitis Plus*, we featured Sherry and her love for driving high-performance cars. Safely suited up and securely strapped in her car, Sherry would take part in what she referred to as "gentlemen's racing", technical driving experiences at up to 150 mph on a road course with sharp twists and turns.

As a member of Athletes Against AS, Sherry helped the group drive home their message and inspire others with spondylitis to remain strong and active. Athletes Against AS wants others to know that spondylitis does not necessarily mean you have to give up your favorite sport if you are a swimmer, enjoy walking, or participate in gentle weight-lifting exercise.

THE SAA WOULD LIKE TO THANK the many friends of Sherry who sent donations in her fond memory.

REFERENCE THE ARTICLE "Two women reaching for their limits...and leveling the playing field" in *Spondylitis Plus*, Winter 2000 edition.

“We Know How It Feels.”

The people who lead Spondylitis Association of America (SAA) educational support groups play a vital role in our support system. We are very grateful to those who have taken on this awesome volunteer responsibility. Here are a few of their stories:

After having suffered six years of oftentimes excruciating pain, and years more of early-morning stiffness and endless fatigue, Mark Swanson was finally diagnosed with ankylosing spondylitis (AS) at the age of 27. He felt devastated and relieved, all at the same time.

Now with a diagnosis in hand, he wasn't quite sure what the next steps might entail. His rheumatologist was supportive and knowledgeable but the 15-minute consultation didn't leave much time left over after the quick discussion about medicines and about the importance of daily stretching and strengthening exercises. What next? Go to the Internet for information? Message boards? Find himself a support group in his area and see if he could meet others with the same disease?

Mark would eventually opt for *all* of the above. A Google® search quickly led him to the Spondylitis Association's website at www.spondylitis.org/—and to an educational support group meeting in his area. It seemed like a good plan to meet with others with whom he could potentially connect in regard to support and to be able to hear about the actual experience from others managing AS on a daily basis.

A diagnosis of a AS or an associated illness can be a frightening experience in a person's life. Though Mark's rheumatologist had been very reassuring by telling him that much could be done to reduce the symptoms, just thinking about having this disease with the unfamiliar name for the rest of his life was very scary. A person in this situation could find himself or herself filled with self-doubt, unable to make decisions. Family members, themselves, are also severely impacted since a chronic disease is a family affair.

Even doctors get chronic diseases

Dr. Martin Cohen, a New York-based psychologist who was diagnosed with AS about 40 years ago, told *Spondylitis Plus*, “I think that support groups can be a very constructive part of the newly diagnosed patient's support team, particularly in the early years of dealing with AS where people typically are very lost, very scared, very isolated, very confused—and very sad.”

Dr. Cohen also points out that some groups encourage partners to attend the meetings. “Oftentimes, it is very helpful to spouses and significant others to hear certain things being said by other people that can make them feel more sympathetic to the struggles their loved one is going through.”

Information and support from others makes a difference

Mike Supancich, M.D., San Diego-area's group leader, retired general ophthalmologist and SAA board member who has had spondylitis for more than 40 years, points out that these support-group meetings can have a positive and calming effect on the newly diagnosed. He says that the atmosphere at the meetings is generally positive and that the information disbursed is solid, factual, sometimes controversial, but always valuable.

“Support groups can be very rewarding and helpful in getting beyond some of the misinformation commonly found on the Internet. Both young individuals and recently diagnosed adults can listen to the experiences of the disease veterans; they're often reassuring. “You wish you didn't have AS, but you do have to live with it and you can live with it,” he said with a very strong emphasis on the word “can.”

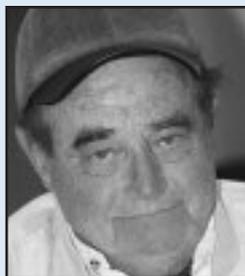
WE SALUTE SOME OF OUR SAN DIEGO SUPPORT GROUP MEMBERS



TIM TOMPKINS



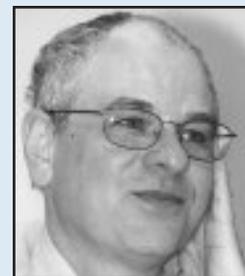
CHERYL STIGALL



MARVIN GOLD



NORINA COLBORN



JAMES HALL JR.

Show Your Support

Are you ready for a group challenge?

Are you interested in starting a new spondylitis educational support group in your area? The SAA would like to help new facilitators get started!

Starting your own group can be a rewarding and challenging experience. Just ask any of the other 20 or so leaders across the country and their legions of members.

As the facilitator of a new group, you will many different hats. Responsibilities include making arrangements for meeting dates and locations in your area; most groups meet once a month or every other month. You will be planning the meeting agenda and lining up speakers, such as physical therapists. You will also respond to your group members' phone calls and e-mail messages.

If you are interested in forming a group in your area, please contact SAA's Programs Coordinator, **Melissa Velez**, who will talk with you about the application process. She's available on e-mail at melissa.velez@spondylitis.org or you can reach her by telephone at 818-981-1616, Ext. 227 or better yet, use SAA's toll-free number within the U.S.: 1-800-777-8189.

TEEN SUPPORT: And if you are a teen with AS, or know a teen with AS, SAA is interested in helping get teens connected to share their experiences as teens with AS. Please contact Melissa Velez for more information.

You may also write to Melissa at this address:
Spondylitis Association of America
 P.O. Box 5872 Sherman Oaks, CA 91413

Dr. Supancich, a support group leader for three years, says he continues to learn from the group meetings: "I've certainly made some good friends. I've learned a lot of practical things, like changing the type of mattress and pillow I used. I now have a latex mattress and pillow. That came up at a meeting where one of the members was considering a latex mattress and pillow. It's all trial and error. Turns out that a substantial number of the people in our group now have latex mattresses. Other suggestions related to rear-view mirror aids and glasses with prisms for individuals with severe neck range-of-motion issues have been helpful; it's ideas of that type that are so valuable over time."

"Peer-to-peer education has a different quality"

Christopher Emerson, a Ph.D. candidate in clinical psychology who is doing his dissertation on chronically ill patients, specifically, "Narratives of Meaning-Making in Women with Ankylosing Spondylitis," said that he thinks peer-to-peer education, the type one finds in a support-group setting, "has a different quality."

He puts it this way: "It's qualitatively different. What I mean is, you can read a brochure or a website, and I think that information gets absorbed intellectually or cognitively, but when you are face to face with a person who has the same lived experience with the same disease, I think the information comes in differently and gets processed differently at more of an affective level; it's more emotional, less about the intellectual and more about the affect or the feeling."

He cautions, however, that much depends on the particular person. "When you are first confronted with others (in a group) who have an advanced disease, that can scare the heck out of you and so you have to ask yourself if that would be good for a newly diagnosed patient and the answer to that is not for some," but then quickly he added, "But I think for most people, the benefits eventually far outweigh the risks."

"I had never met anyone else with AS"

Roger Stead is a long-standing spondylitis educational support group leader in the metro Washington D.C. area. Diagnosed while serving in Vietnam in 1966 where the onset of AS came on surely and dramatically, he says he felt lucky to get the diagnosis, even though it came at the very end of his tour duty and he had already suffered through his combat days. "I remember having guard duty responsibility at night and the pain was bringing me to tears and I still had to perform my duty." "Speaking for myself," Roger says, "I came home from the Army, and I had never met anyone with AS; I didn't find anybody else with AS until seven years ago."

And for the past six years, he's been leading his own support group. He explains what motivates him: "Most people go through life feeling

alone. You still don't meet anyone just reading about the disease. The first function of the support group is that you actually meet other people face to face. I think it makes you feel that you're finally not alone. You see other people and especially the older ones, and you say, 'OK, this is not going to affect my mortality. They're making it through life—and they're 70 or 80 years old.' That's uplifting."

He notes out that the most important thing he can say about a spondylitis support group, is that "they are not a program where you stand up and say, 'Hi, I'm so and so and I have AS.'"

Roger also points out that, unlike anonymous posting to the Internet, you get immediate, personal feedback to your questions and concerns and that you also "get to interact with other people without feeling self-conscious." "If you have to stand and stretch and turn your whole body to look at someone to talk to someone, you don't feel self-conscious about it."

"It's been very rewarding"

Richard Powell, Houston group leader of three years says that Dr. John Reveille, Principal Investigator of the AS Genetic Family Study and long-standing member of the SAA Medical Board, asked him a couple of years ago if he would have any interest in running a spondylitis support group in Houston. He agreed to try it out and hasn't looked back, adding "and it's been very rewarding."

"Sometimes, it can be frustrating because we'll have all these plans and only six or seven people show up and then when you least suspect it, that number will swell to 35; it's rewarding even if you bring relief to just one person; you feel you've done your job," Richard says with pride. "That's just the way I look at it. That week, if you help one person deal with the intrinsic problems associated with AS, then you've survived and you're doing a good job; that's what we have to do, go on in spite of the disease."

As for the ranks of the newly diagnosed people, Richard says that if anyone is struggling, he reaches out to them to put them at ease with the struggling, "because of what I went through." Richard makes himself personally available for one-on-one meetings after his bi-monthly agenda, too.

He adds with the voice of a certain wisdom garnered through his own experience: "That's why I do it; I suffered so long without knowing what was going on or how to deal with it, being misdiagnosed for so long. Finally, once I was correctly diagnosed, it was just very, very gratifying to be able, to be asked, would I consider doing this? I wanted to help others avoid the pitfalls I went through. It's scary for someone who has never heard of the disease. There's no cure. That's also pretty scary. But the disease is manageable and the more you understand how to manage the disease with the right medications, the right physical therapy and exercise, you can live a life that's worth living."

SPECIAL THANKS

"... it's more emotional, less about the intellectual..."

The SAA would like to acknowledge these Spondylitis Educational Support Group leaders who have volunteered their time and energy to facilitate their groups. On behalf of the SAA and the hundreds of people you have helped with spondylitis, we extend our sincere appreciation and thanks to:

Glendale, AZJohn Kornfeind
 Long Beach, CABarbara Crofut
 Long Beach, CAFrances Tomich
 Los Angeles, CAJanelle Haider
 Orange County, CAKyle Brownfield
 San Diego, CAMike Supancich
 San Francisco, CAClarence So
 Fort Wayne, INKen Prather
 Indianapolis, INKen Prather
 Kansas City, MOLinea Cooley
 Detroit, MI.....Laura Russell
 Holland, MIScott May
 Cleveland, OHBryan Andresen
 Portland, ORKen Henschel
 Philadelphia, PA.....Howard Tevelson
 Myrtle Beach, SC.....Alex Best
 Houston, TX.....Richard Powell
 Washington, DCRoger Stead
 Seattle, WAPaul Stevenson

The Chicago, IL Spondylitis Educational Support Group is looking for a new leader. Contact Melissa Velez at (800) 777-8189, x227 if you are interested in learning how to become a leader.

Detroit, MI now has a Spondylitis Educational Support Group! Support online from NY, NY with Michael T. Smith, spenser23@aol.com.

Charity Navigator Awards SAA ★★★★★ Rating



The Spondylitis Association of America is pleased to announce that we have earned our second consecutive 4-star rating from Charity Navigator, the largest independent evaluator of charitable organizations in the nation. We were awarded this rating for our ability to efficiently allocate and grow our donated finances.

Fewer than 12% of the charities rated by Charity Navigator have received two consecutive 4-star evaluations, indicating that SAA outperforms most charities in America in terms of financial responsibility.

This "exceptional" rating from Charity Navigator differentiates SAA from our peers and proves that our organization is worthy of the trust our members and donors have shown us. To view our page on the Charity Navigator web site, go to: <http://www.charitynavigator.org/index.cfm/bay/search.summary/orgid/9809.htm>

So know that when you give to SAA, you truly are helping us in our 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. To learn how you can support the SAA, call (800) 777-8189 or visit our web site at www.spondylitis.org.

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:

Glendale, AZ	John Kornfeind	(623) 910-4742	jmmkorn@cox.net
Long Beach, CA	Barbara Crofut	(562) 421-9698	crofutgr@netzero.net
Long Beach, CA	Frances Tomich	(562) 429-9685	N/A
Los Angeles, CA	Janelle Haider	(310) 279-0504	saa_la_ca@yahoo.com
Orange County, CA	Ms. Kyle Brownfield	(949) 367-0430	kylebrownfield@msn.com
San Diego, CA	Mike Supancich	(760) 438-2962	supancichsr@sbcglobal.net
San Francisco, CA	Clarence So	(415) 297-2803	clarence@clarenceso.com
Fort Wayne, IN	Ken Prather	(260) 637-1705	pratherken@yahoo.com
Indianapolis, IN	Ken Prather	(260) 637-1705	pratherken@yahoo.com
Kansas City, MO	Linea Cooley	(913) 384-0728	linea_cooley@hotmail.com
Augusta, ME	Michelle Andrews	(207) 445-2885	qualey28@adelphia.net
Detroit, MI	Laura Russell	(586) 598-4745	mrussell.21@netzero.com
Holland, MI	Scott May	(616) 610-9130	smay@wmis.net
Cleveland, OH	Bryan Andresen	N/A	bnkandresen@adelphia.net
Portland, OR	Ken Henschel	(503) 579-8375	Ken.Henschel@comcast.net
Philadelphia, PA	Howard Tevelson	(215) 844-6075	hotbyht@yahoo.com
Myrtle Beach, SC	Alex Best	(843) 655-9762	alexbest@ss.rr.com
Houston, TX	Richard Powell	(409) 883-7822	rwpowell@gt.rr.com
Washington DC	Roger Stead	(703) 455-6005	rogerstead@aol.com
Seattle, WA	Paul Stevenson	(206) 524-2186	pastev@Safeco.com

Support online from NY, NY with Michael T. Smith spenser23@aol.com

Online Poll

You can find this new Instant Poll on our website at www.spondylitis.org.

NEW POLL

Which medical professional do you see most often?

- Primary Care Physician
- Rheumatologist
- Occupational Therapist
- Physical Therapist
- Gastroenterologist
- Dermatologist
- Other

OLD POLL RESULTS

I would attend a spondylitis support group meeting if it offered:

- All of the above80%
- Current information and education 4%
- Speakers who are knowledgeable about spondylitis 4%
- Literature and materials about these diseases 4%
- Opportunities to educate the public4%
- I would not attend a meeting4%
- Confidential, non-judgmental interaction with others0%

Medical and Scientific Advisory Board

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Reach Out and Touch Someone!

The SAA wants to help people with spondyloarthritis (AS or a related disease) connect with others in locations across the U.S. where a support group has not yet been established.



Chad Cavender in Macon, GA would like to meet others in his area with spondyloarthritis. If you live in Georgia and would like to "reach out" to Chad by telephone or mail/email, please contact Melissa Velez, Programs Coordinator, at melissa.velez@spondylitis.org and she will put you in touch.

Beat the heat! Get in the water!

Follow Bruce Furniss, former Olympic Gold Medalist who with AS, as he demonstrates fun and easy exercises for swimmers and non-swimmers alike. Get your "Water Workout" exercise video today for \$15.

To order call (800) 777-8189 or access our secure server at www.spondylitis.org to purchase with a credit card.

ARE YOU WILLING TO HELP RESEARCHERS FIND THE GENES THAT DETERMINE THE SEVERITY OF ANKYLOSING SPONDYLITIS?

If so, you may be interested in participating in our study. To participate you need to be at least 18 years of age or older and have been diagnosed with Ankylosing Spondylitis.

Who is conducting the study?

The study is sponsored by the National Institutes of Health (NIH). The doctors conducting this study are Dr. Michael Weisman at Cedars-Sinai Medical Center in Los Angeles, Dr. John Davis at the University of California, San Francisco, Dr. John Reveille at the University of Texas at Houston, and Dr. Michael Ward at the National Institutes of Health in Bethesda, MD.

How can I find out more?

Please contact one of the following Study Coordinators for more information:

- **Southern California:** Felice Lin, (310) 423-2422, linf@cshs.org
- **Northern California:** Stephanie Morgan, (415) 502.1698, smorgan@medicine.ucsf.edu
- **Houston Area:** Laura Diekman, (713) 500.6852, laura.diekman@uth.tmc.edu
- **Washington DC Area:** Lori Guthrie, (301) 435.8434, guthriel@mail.nih.gov

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.

LOG IN

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

www.spondylitis.org

Save the Date!



Spondylitis Association of America™

P.O. Box 5872
Sherman Oaks, CA 91403

JOIN US IN WASHINGTON, D.C.
for an all-day
SAA spondyloarthritis
educational seminar on
SATURDAY, NOVEMBER 11, 2006.

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