

SPONDYLITIS PLUS

may/june 2006



TYLER WALKER
A MOTHER'S STORY

INTRODUCING SAA'S
NEW EXECUTIVE DIRECTOR

NEW GENES MAY MEAN
NEW TREATMENT FOR
A.S. POPULATION

MASSAGE THERAPY
HELPFUL TIPS

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 six 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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The season is truly changing at the Spondylitis Association of America. Our Co-Founder and Executive Director, Jane Bruckel, will be retiring effective July 7, and our new Executive Director, Katherine Culpepper will take the reins on July 10.

Many of you have expressed your sincere gratitude to Jane Bruckel during these past few months. But can words ever express the gratitude felt by all of us who have been touched by Jane's work of the last 23 years? Humble beginnings led to monumental achievements in research, patient advocacy and education.

There will be many opportunities to honor and thank Jane for her many accomplishments on behalf of those diagnosed with AS and related diseases. Recently, the Board of Directors unveiled the Jane Bruckel Research Fund in her honor. Another way to honor Jane was to make sure the organization she nurtured to success over so many years is left in capable hands. To that end, your Board of Directors at SAA has been hard at work this Spring, seeking to identify the next generation of leadership. We followed a rigorous process, including engaging a third party consultant, to ensure we cast as wide a net as possible to fill this important post. SAA is fortunate to have a reputation for smarts and integrity in the medical community, to be in sound financial condition with a four-star Charity Navigator rating, and to enjoy the talents of an outstanding staff. These factors made our job much easier than the executive transitions faced by many non-profits where a longstanding founder is retiring.

We are pleased to say this hard work—both by the Board this Spring and by the organization as a whole over 23 years—has paid off. We are fortunate to have found a new SAA Executive Director with the experience and compassion to take SAA to new heights. Katherine Culpepper has joined SAA as our new Executive Director after a lengthy career in non-profit management, most recently as the Executive Director of a national nonprofit group devoted to making life easier for chronically ill children. Katherine does not have AS, but understands the burden of chronic disease from her past experience. Her management, fundraising, and public relations experience will be invaluable to SAA as we continue to advocate for patients, provide greater public awareness of the diseases, and seek funds to accomplish our mission for a cure.

We salute both the successes of the past under Jane's leadership, and the promise of the future with Katherine at the helm. Please join us in welcoming Katherine to SAA.

David

David Hallegua, M.D.
 SAA Chairman

Erratum

In the March/April issue, please note that the names of SAA's first Board of Directors listed on page 5 should have read, (L) Neil Monick, Susan Stehn, Mary Ann Sears, Buck Buchanan (late) and Mike Ellis, Jane Bruckel (not included).



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Dear Editor:

Thank you so much for all of the helpful words and support that you have given me through the years. The last issue of *Spondylitis Plus* gave me information about the rib cage problems I had for years and previously had not seen much written up about this pain and misery. Also, my neck is fused completely and the pain has been unbearable. The only thing that has worked for me was the cortisone. I cannot drive anymore.

I would like to get a spondylitis support group going in this area. The closest group is in Houston, north of here.

Keep up the good work. I am really impressed with how much you all have done to make the doctors more aware of this disease and also realize that women get it too. Forty years ago, I was told only men got this disease...thank you for enlightening them.

Sincerely,
Anna Johnson
San Antonio, TX

Editor's note: If you are interested in starting a spondylitis support group in the San Antonio, TX area please contact Melissa Velez, Programs Coordinator, by email at melissa.velez@spondylitis.org or call (800) 777-8189, extension 227

Dear Editor:

I have AS with the normal head forward position. If I lay down on a flat surface, my bed or table, my head will not touch. After some time, the middle of my back will adjust, as if adjusted by a chiropractor, and my head will be closer to the table. However, when I go to get up, the muscles in my chest

and diaphragm area are so splinted and tight, that it takes me ten minutes or so before I can comfortably start walking. Do other people with AS have the same issue? Is there any corrective treatment for this?

Thank you,
Tom

Editor's note. We have contacted the SAA Medical Board with this question and will let you know what we hear. If other readers have an experience to share in this regard, please write to us at this column – laurie.savage@spondylitis.org

Dear Editor:

My husband had spondylitis for many years – and in his mid 50's started developing the stooped-neck position. None of the medications helped him very much for the pain, but the inability to look ahead and then to eat very easily was a true thorn in his side. He started asking about possible surgery and his rheumatologist, while not in favor of it because of its seriousness, started doing some research for him.

Ultimately he was sent to University of California San Francisco Medical Center and had surgery. It was completely successful, although very difficult and it took a very long time to heal. His head had been stooped to within two fingers of his chest. When he came home, he marveled at the fact that he could just stand and look out at our backyard and see how beautiful it was.

Unfortunately, he developed lymphoma and died four years after his surgery. The lymphoma had absolutely nothing to do with the surgery.

I read your magazine cover to cover every

time it comes and often wonder why there is not anything written about this surgery. Granted, it is very serious and you must be sure that the surgeon you use has performed these surgeries, but when you are suffering with pain all the time, how nice is it to not suffer the difficulties presented with the “stiff-stooped neck position” as well. My husband recommended it to anyone he could.

I would think with the sources available to you, an informative article would be helpful to those suffering with this aspect of the disease. I believe something was in one of your magazine some years ago – but I believe it should be discussed again.

Sincerely,
Jan (Carter) Lloyd

*Editor's note: Thank you for taking the time to express these suggestions. Prior to his passing, we had the pleasure of working with your late husband, Childs Carter, on several occasions. Please know that it is our intention to write about the corrective procedures associated with AS in upcoming issues of *Spondylitis Plus*. As you rightly point out, these are critical issues to many of our readers. Thank you for your ongoing support.*

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:

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Letters to Editor/SAA

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New Genes May Mean New Treatments for AS Populations



John D. Reveille, MD

You could call Dr. John Reveille the “Christopher Columbus of Ankylosing Spondylitis” in that he is again off and running in an attempt to discover new genes involved in the complex disease. Once mapped, he says, the new genes will allow some exciting treatments to be formulated.

“We have novel treatments that make a difference in the disease now,” he told an audience of AS patients in Houston at a SAA-sponsored conference in late April, “and with these new studies, we pin down new genes and we potentially get new treatments.”

“History of the World—and AS—in 45 Minutes”

Dr. Reveille, SAA Medical and Scientific board member and Director and Professor of Medicine, Division of Rheumatology and Clinical

Immunogenetics at the University of Texas Health Sciences Center at Houston, traced the history of AS and genetics in his talk called, *“A History of the World and AS in 45 Minutes.”* He had the undivided attention of about 100 AS patients, primarily from the Houston and Dallas areas, as he traced the routes of human migration using anthropological and genetic information. “Current fossil data suggest that our ancestors came from one place: Ethiopia,” he said as the group looked around the room at one another.

“Our earliest ancestors go back over five million years. The modern species of man, homo sapiens, goes back some 200,000 years,” Dr. Reveille explained. The theory that people from Africa left the continent through Egypt and migrated through the Middle East into Europe and Asia, finally into Australia and China around 50,000 years ago was explored—along with the great genetic diversity and ensuing consequences that was created. “Most of the ancient history of man took place in Africa; only more recently did we get man traveling everywhere else,” he said, describing how our genes dispersed themselves around the world.

Learning By Peering Back in Time

Dr. Reveille explained to the group that a gene is an ordered sequence of DNA that encodes a specific protein on a particular chromosome that, in turn, causes a specific bodily function to occur. “A gene makes a protein; skin, hair, enzymes—all genes exist in certain forms called alleles,” he said, going on to explain our set of 23 chromosomes that makes up every human.

So DNA is a vast chemical information database that carries the complete set of instructions for making all the proteins a cell will ever need. Each gene contains a particular set of instructions, usually coding for a particular protein.

“You can delve through history by looking at genes,” he said, his voice rising. There are special ways this is done: “one is to look at mitochondrial DNA, which only comes from our mother and is not inherited in the same fashion as other DNA that is found in the cell’s nucleus. If you track the mother’s DNA, you can trace our roots in various parts of the world.” The other is to look at the “Y” chromosome DNA, which comes only from the father

Dr. Reveille’s carefully produced visuals did a yeoman’s job in teaching the crowd that the best-known genes in the major histocompatibility (MHC) region, where evolutionary biologists find lucrative grounds for study due to the high levels of diversity found within these genes, are the subset that encodes a special type of cell-surface antigen-presenting proteins. Antigens include bacteria and environmental toxins. In humans, these genes are referred to as human leukocyte antigen (HLA) genes, although people often use the abbreviation MHC to refer to HLA gene products.

And then, with the genetic cellular and molecular basics down pat, Dr. Reveille tied up all the information as it pertains to spondylitis:

Reporting from the SAA Educational Meeting in Houston

Genes and Their Links to Ankylosing Spondylitis

“When we talk about these various genes within the MHC, they are a large gene family, which play an important role in the immune system—and in autoimmunity,” Dr. Reveille said. He then paused dramatically, gazed directly at the Saturday-gathered crowd and said in a booming voice, “HLA genes dictate how we deal with the environment—and most of the people in this room have HLA-B27.” The group uniformly nodded their heads in unison in response and smiled broadly at the familiar territory. “Ah, ha!” some of them were heard to have said.

Dr. Reveille soldiered on while the stalwart Lone Star State crowd followed: “There are more than 675 types of HLA-B; this particular HLA (as opposed to HLA-A, HLA-C, HLA-DPA1, HLA-DPB1, HLA-DQA1, HLA-DQB1, HLA-DRA and HLA-DRB1) is the one that comes in the most different forms and these are very, very important in that they’re a computer program of how your immune system works within the environment and they have all evolved from dealing with the various stresses since the beginning of time.”

But now, over the past 150 or so years, instead of the environment changing us, Dr. Reveille said, we have changed the environment. “If you look at what killed ancient man, it was largely infection, malaria, plague, small pox, typhus; now, it is heart disease, diabetes, cancers—and new infections that were never even around before. We have altered the environment and now the environment may be striking back in ways we never anticipated. What has happened, is that over the past 150 years, the paradigm has been altered and now the genes themselves are causing mischief.”

He was preaching to the proverbial spondylitis choir with this one. Some of the attendees leaned forward at this point, not to better hear him, but to just be nearer to the enlightening source of information. “Without infections to keep the immune system occupied, we have instead seen the appearance of autoimmunity, where the immune system turns on the body itself; I’m afraid that we are paying the price for making the planet more livable,” Dr. Reveille said into his portable mike.

HLA-B27 – A Conundrum

He explained that populations with HLA-B27 have a distinct advantage in dealing with certain infections and environmental stresses, such influenza and even in HIV (where the infected patient is documented to live twice as long as those with HIV who lack HLA-B27. “In fact, HLA associations with certain diseases carry over to virtually every single specialty of medicine—so how does that relate to AS?” he asked.

In order to make the point that AS has been around for ages and ages, Dr. Reveille pointed to such historical figures as Pharaoh Ramses II (“Ramses the Great”), with his “bamboo spine.” Even the ancient Egyptian ruler’s great, great, great grandfather Amenhotep IV had the disease. Among the Egyptian pharaohs, it’s easy to understand how all the AS was aggregating in those families: they often married their sisters, concentrating genes in one

place,” he said. More modern AS figures included St. Alphonsus Liguori, patron of theologians (“It’s not hard to see what kind of arthritis he had,” Dr. Reveille noted as he flashed a slide showing the venerable saint with his head bent to his chest); and even Pope John Paul II, with his curvature of the spine that forced him into a stooped position. HLA-B27 is found in more than 90-percent of the Caucasian population today. “In other words,” Dr. Reveille pointed out, “one-in-every-15 people of Caucasian descent walking down the street has B27, but only five percent goes on to develop AS. That means 95 percent do not develop it.”

Continued on page 6



Richard Powell, Houston Spondylitis Support Group Leader (pictures bottom left), enjoyed the seminar with our other attendees.

Photo credit: Kristina Anderson



Joe Ann Morris
Houston, TX

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“Something More Is Going On Here”

Looking directly at the B27-heavy audience, he pointed his index finger at them and said, “And all of you here with AS, about one out of five of your relatives who have HLA-B27 will develop AS or some other type of spondyloarthritis; something more is going on here, so it’s a question of finding out what the other genes are.

Other AS Genes Are Hiding

“Our research to date tells us that other genes for AS are to be found on other “involved” chromosomes and it’s now a question of digging them out and mapping them—and that’s exactly what we’re doing right now,” Dr. Reveille said to the enthusiastically approving crowd.

Most of these are “small effect” genes that by themselves do little to contribute to AS, but work in concert with one another, where the cumulative effect of the interaction is this disease. Now, these genes not only cause AS; they also keep plugging away in terms of how the disease manifests itself in the AS patient. For example, these genes may also control the age of AS onset and the severity of disease—and complications, such as uveitis, iritis, inflammatory bowel disease, spine fusion and destruction of joints.

*“You can delve through history
by looking at genes...”*

“Each one of these genes does not act in a vacuum,” Dr. Reveille pointed out. “They act inside of each one of us along with all the other genes, along with non-genetic things in the environment—such as how much money we have, how happy or sad we are, how educated we are, what kind of work we do—all those non-genetic factors we have that influence certain traits that give rise to disease.”

The researchers already have positive results from the first arm of their project, the SAA AS Family Genetic Study and the North American Spondylitis Consortium in which hundreds of generous individuals from around the country participated. “There’s little question we should completely dissect the genetic susceptibility in the second arm of this research project,” Dr. Reveille maintained.*

He concluded the presentation, “With this research, we can ultimately get this cruel disease under control, even more than we have with the anti-TNF-a drugs; we can find those people at risk and get an earlier diagnosis, and possibly cure the disease from the very onset.”

*The “involved chromosomes” reference is based on genome-wide scans developed by Dr. Reveille and his colleagues that has already implicated regions on chromosomes 2q, 6p, 6q, 10q, 11q, 16q, 17q, and 19q in ankylosing spondylitis, on 4, 6p, and 17q in psoriasis, and on 7q and 16q in inflammatory bowel disease.

STAY IN TOUCH

To ensure that you do not miss any issues of *Spondylitis Plus* or other SAA correspondence, please let us know when you move or replace your email address.

Contact Linda Powell by telephone (818) 981-1616 or email info@spondylitis.org so that we can stay in touch

AS Diagnosis in Children Can Be Difficult To Obtain

After a harrowing night spent in an Orange County, Calif. hospital, Diana and Rick Annett took their highly traumatized 14-year-old son, Brian, who was loaded from a wheel chair into the family van in the exact same condition in which he was admitted, and went home without a diagnosis.

When they had arrived at the doctor's office the previous day, in February 2005, the champion swimmer couldn't walk. He had just worked out the day before. He was ordered to go to one hospital and then was quickly transferred to another, more specialized medical facility.

And he was screaming from the pain all the while. "You couldn't even touch his legs," his mother remembers, her youthful voice cracking. "That's how sensitive they were; we had to carry him to the car and get a wheelchair, and just moving his legs was horrific."

"They were thinking it was maybe something to do with his spinal cord. You can imagine the scary things they were thinking and what I was trying not to think about," Mrs. Annett, who is still shaken when reliving the details, tells *Spondylitis Plus*. Brian had had a few previous trips to the ER, where his pain was diagnosed as "lactic acid build up," even though it is now known that lactic acid is actually a fuel, and not a caustic waste product.

It has been known for a long time that there is a close connection between the HLA-B27 allele and ankylosing spondylitis. The initial treating physician, an orthopedic surgeon, had in fact ordered this very test for Brian, whose sister has psoriatic arthritis.

So armed with the Rosetta stone to the disease—even though she didn't realize it at the time—Mrs. Annett repeatedly inquired of the hospital staff doctors if this positive gene test was related to her son's worsening condition. Everyone, however, was baffled as to his condition. They couldn't find anything physically wrong with him, and his spinal MRS and labs were normal. The neurologist and an infectious disease specialist could only shake their heads at the family as the lanky youth lay writhing in the hospital bed.

Still No Answers....

The next morning Mrs. Annett was told by the doctors that even if their daughter did have psoriatic arthritis, their son did not have the arthritis that was associated with a positive HLA-B27. "They pooh-poohed it when I told them the 'orthopedist' said the test might be important," she said, adding that based on the test, she had requested that a rheumatologist see her son no fewer than three times. Each time, her request was refused.

"Then I had this infectious disease doctor look straight at me and tell me that it was all in Brian's head. 'I think you're putting too much pressure on Brian

with the swimming; he needs time to be a kid,' he told me," recalled Mrs. Annett, who says she took quivering and angry umbrage at the suggestion. "I then looked at this man and said, 'You have just met my son; you haven't even talked to our family.' He had no information about us. None of that. They didn't ask about his daily routines. Had they known, Brian has oodles of time to be a kid. I was ready to scream and yell, but I maintained my manners," Mrs. Annett explained, to this day still emotionally reeling from the family's hospital ordeal.

Mrs Annett Feared The Worse

"When I walked back in there," Mrs. Annett said in picking up the story, "Brian's face was like a ghost. Here's this 14-year-old kid lying there with severe pain. His eyes were half opened. There was something that had been taken from him. I looked at him and I wanted to cry because I didn't know what words had been exchanged. I thought, 'you know what, I've got to get my kid out of here.' They had already done some mental damage to him, making him feel that this horrible pain was in his head. He later told me the doctor made him feel like he was crazy; he had actually suggested that to him."



Tyler Walker & Brian Annett

So the Annett family got Brian to his sister's rheumatologist, Dr. William C. Shiel of Mission Viejo, Calif., the following week. Dr. Shiel diagnosed him with AS after a careful history taking and a five-minute examination where Brian came up quite short on flexibility, plus the positive HLA-B27.

Sometimes Counseling Can Help Sort Out Emotions

Brian had a couple of counseling sessions to help him deal with his hospital ordeal, where he was told that his pain was all in his head, that it was somehow his own fault for giving in to it. "Even though we said both those doctors were wrong, it was helpful to have the counselor tell him that he didn't do anything wrong," Mrs. Annett notes.

Dr. Shiel knows Brian loves to swim and he's doing everything in his power to help him achieve his goals. Brian, who turns 16 in September, is now a sophomore in high school and is back on the Mission Viejo Nadadores club team. His specialty is the 100-yard backstroke. This year, Brian has achieved CIF status for Mission Viejo High School, where they just won Division I, CIF. "He got to be a part of that, which was really cool," his mother happily reported.

He recently began treatment with an anti-TNF-a blocker. Ms. Walker told *Spondylitis Plus* that the pain in his lungs is on the wane and that the arthritis in his hips, knees and ankles is also getting better. She said she no longer hears him moaning in pain during the nighttime hours.

"I will fall to my knees and cry if it is all working for him," she swears, getting back to the pre-diagnosis days one last time. "It's just so maddening. I just don't want these people to do to another family what they did to us. I don't want them to look at another sweet child they've just met and say it's all in his frickin' head. It's unfair. It's mean. It infuriates me. It could have been avoided."

A Mother's Story: 'Please don't let this be'

Over a period of weeks, Sherri Walker noticed that when her nine-year-old son, Tyler, got out of bed in the morning, he exhibited an unusual stiffness in his walk that didn't go away. A warning went off in her heart, where she knew what it was, but she wasn't ready to put a name on it—not yet. "Dear God, please don't let this be what I think it is," she would pray. But the stiffness continued unabated, although the happy little swim team member never complained about it.

"I actually watched him get up in the mornings and he would get out of bed stiff-legged," Mrs. Walker recalls. "That alarm kept going off—and I knew what it was because I thought I could have it and my mother had just been diagnosed with it after years of having what we thought was just arthritis and my mother's sister has some form of it and their mother had arthritis."



Left: Tyler Walker at age 5 with Trophy & Medals



Bottom: Tyler Walker Sleeping with Trophy

The "It" Is, Of Course, Ankylosing Spondylitis

The "it" Mrs. Walker refers to is, of course, ankylosing spondylitis, but getting the youngster tested and diagnosed for the disease would be another matter. "First I had to get approval from our primary care doctor who said, 'No, Tyler doesn't have arthritis—he's nine—what are you talking about?'" He really fought me and I explained to him how the disease ran in our family, but still, he initially wouldn't approve the tests," Ms. Walker recalls for *Spondylitis Plus*.

"Finally, finally, finally, he said, all right," the Orange County-based advertising copywriter continues. "The blood test was HLA-B27 positive—and there it was. They did an entire battery of tests, mostly to rule out other illnesses. It took about six months to go from 'something is wrong with my son' to finally seeing an expert who could help us."

That expert was UCLA's chief of the section on rheumatology, Dr. Deborah McCurdy, who Mrs. Walker called "fabulous and wonderful." Dr. McCurdy wrote to Tyler's school, and requested that Tyler be given an extra set of textbooks so he wouldn't have to ferry them around on his back, a move his mother termed "invaluable"; the books should have been provided to him free of charge under IDEA* (see sidebar).

Tyler Wanted That Trophy

Meanwhile, Tyler wasn't letting the morning stiffness and soreness get in the way of his childhood dreams of become a swimming champion. He had been swimming competitively since he was five years of age after eyeing his friend's trophy. "I just thought that my friend's trophy was so cool and I wanted one for my bedroom," Tyler says. So Tyler's career as a competitive swimmer was off and running at the age of five. He started out on the Rancho Santa Margarita Dolphins, a small city local team

The more his parents learned about his diagnosis, the happier they were at his choice of activity. "Tyler's dad was so supportive of his swimming and of me when we were taking Tyler to the doctors who told us there wasn't anything wrong with him," notes Mrs. Walker.

The youngster later joined the prestigious Mission Viejo Nadadores swim club. He also swims for his Tesoro High School team where he holds school records in the 100 butterfly stroke and 500 freestyle. And the scholar-athlete's impressive grade point average has remained at 4.0 for the past three years.

Tyler, now 17, just broke his own school record in 100-yard butterfly on Saturday, May 13 at the CIF Swim Finals in Long Beach. He swam a 52.87; his school record last year was 53.27.

He says the hardest thing about having AS since he was a little boy is not always being able to do what the other kids do: "I remember back in the sixth grade—they all went out and jumped rope on the basketball court. I did it, too, but then I had trouble walking the next day from the pressure and the pounding on my body. I had to eventually get out of PE because I couldn't do the same activities as the other kids. But I could swim. That's what's great about swimming; it's not that much pressure on the body and it doesn't take a toll."

e what I think it is...'

“Not That Many People Know About AS”

Tyler says that naturally his teammates don't know about ankylosing spondylitis so he refers to his disease only as “arthritis.” “Not that many people know about AS. The disease name sounds so technical that it's not even a ‘human thing’ anymore so I tell people that I have arthritis, which everyone understands. I've always felt like I was the same as everyone else, but that I just have had to be more careful. I've had more things to worry about and I've had a few more setbacks,” he mentions.

Although Tyler's symptoms are mostly controlled with prescription dosage nonsteroidal anti-inflammatory drugs, he still gets occasional painful flare-ups that can sideline him from his swimming meets. Recently, although he says he has built up a “good resistance to pain,” he had to bow out of a couple of important swim meets that caused his coach and teammates to think he was malingering, something he wasn't comfortable with defending.

“We had a big high school meet and I hurt my neck and it was really stiff. Somehow, I must have pulled it,” Tyler recalls. “I think the arthritis made it worse. I was just having a lot of trouble moving. You never realize how important something is till you don't have the use of it. It's amazing how little mobility you have when your neck is injured. I couldn't swim. I told my coach I was sorry I couldn't make it. He understood but he was very frustrated; he said they needed me.”

The next time was a league meet the following week. This time his hip was involved in the pain cycle. He couldn't walk. His mother let him sleep in the morning of the competition, thinking they could evaluate his condition after a lengthy rest. But he realized he couldn't swim due to the agonizing pain. He had to notify the coach. The coach bellowed into the phone, “You've got to be freakin' kidding me! The line-up is built around you!”

“We Need You, Tyler...”

Within a few minutes, Tyler started getting calls from his teammates. “Tyler, we need you,” they pleaded to him. Tyler says he “felt horrible” not being able to be there and support his team. “It was so disappointing to let my team down. I wanted to be there. I just couldn't; I was in a lot of pain and I couldn't move.”

Today, Tyler is in a different swim group and Ms. Walker was thrilled when the new coach asked her for literature and information on AS. She tells us what happened: “Tyler's new swim coach, Ryan Purdy, actually asked me to send him info on the disease so he could read up on it and know what he's dealing with. That's never, ever happened with any other coach. I sent him the info and he e-mailed me back, thanking me, and I'm sure he will be incorporating some of this new knowledge into Tyler's swim training. It's very encouraging.”

Tyler's bedroom walls are now lined with prize-winning swimming trophies. “Swimming has been a great experience for me,” Tyler says, and yes, he notes that he will most likely continue swimming in college where his sights are set on attending UCLA.

He notes, “Swimming is a team effort and I enjoy the social aspect—and the whole team roots for you, too.”



Tyler Walker in his teens

What A Great IDEA: Individuals with Disabilities Education Act

But parents need to know about it. Mrs. Walker tells *Spondylitis Plus* that she had no idea about IDEA. “I've been borrowing these books and purchasing these books for Tyler all these years,” she laments when informed that the books should have been provided for him under the Act.

The individuals with Disabilities Education Act (IDEA) provide funds to states for the education of children with disabilities; ankylosing spondylitis qualifies for the funds. It assures that each child with a disability receives a free appropriate public education (FAPE), usually between the ages of three and 21. Each child receiving services has an individual education program that spells out their needs. Parents are involved in the planning of the services. Currently, all states receive IDEA funding in the form of federal grants to each state.

Visit the Department of Education to download an informative 26 page brochure on this topic:
http://www.house.gov/ed_workforce/issues/109th/education/idea/ideaafaq.pdf

My Story

ACCEPTANCE WAS NOT EASY



Dear Editor:

I just reread the letter to editor from Mary Beth in the Nov/Dec '05 issue. She talked about some of her fears and asked how we deal with them. She also mentioned she lives life like she is 80 - always being careful. Since I am 71 and seem to be rapidly approaching 80 I would like to tell her a little bit about my experience.

My AS started in my lower spine when I was about 20. It was diagnosed as a 'tilted' spine and other things over the years. I was finally diagnosed with AS in my mid-30s and shortly after that my spine was fully fused. During and after this time I stayed active. One of my favorite activities was cross-country skiing. I was aware that I couldn't afford to fall - it made the skiing a pretty intense and enjoyable experience for me - I never did fall but I do have a picture of myself with one ski totally off the ground and poles flying up in the air.

The only AS related auto accident I had was backing out of my driveway one Sunday morning and I bumped my neighbors car because I didn't see him coming. (I was in a hurry to go get a Mothers Day present for my wife before she got home from church! - I still got the present.) I still drive but I do plan my routes so I don't have to make a left turn onto a busy street unless there is a stop light. I also pretty much stay in line with plenty of space to the car in front even if I may prefer to go a little faster. In many ways, I probably drive more safely because of my disease. I do get uneasy when riding with someone who tailgates - especially if they don't seem to be giving 100% of their attention to driving. Our highways are a pretty scary place to be with or without

AS. More Americans have died on our highways than have died in all the wars we have fought in. We bought a retirement home with a circular drive so I don't back onto the street anymore (especially on Mothers' Day). I look for drive thru parking spaces in parking lots and use mirrors a lot.

In retrospect, things have been better for me after the spine fusion was completed. As long as I stay within limits, I no longer have any significant pain. I have had flare-ups in my feet and hands but Aleve or equivalent seems to make that tolerable. My wife and I just got back from a getaway to the NC mountains. I love to walk/hike (but not on rock or ledges). One day I walked 8 miles on woods trails and then

Woody's Life Lessons / See Next Page

played 18 holes of golf (walking) on a short but hilly course. I try to walk 15 miles or more a week. I also do exercises - resistance training with weights about three times a week to get my heart rate up and maintain my strength.

Acceptance wasn't easy. I think that staying busy helped a lot - my job, my family, projects around the house - I was able to do such things as building good size decks at our home and our vacation home. Because of other issues in my life I became a member of a twelve step support group. They readily accepted me. I learned I was powerless over many things including the fact that I had AS. I learned that I had no control over the AS disease but I did have control over how I dealt with it and my attitude. I have many characteristics - some I like and some I don't like so much - I am human. We are all different but we are all special.

*“One day
I walked eight miles...”*

I learned some great life lessons from AS:

- I have found it best to walk through the pain of my AS and try not to let it slow me down too much. It is the same for other pains I encounter, emotional or physical—facing those pains and walking through them generally works best.
- My disease reminds me that I have many limitations. I have to accept those and rely on God.
- I look strange to other people because I am so stiff. Well, I am strange—others don't know me and I don't know them. But if we both take the time and effort to get acquainted then we won't remain strangers.
- I may pass this disease on to children and grandchildren. One grandchild has spondylitis so I know this is real. There is so much else I pass on as well—primarily by how I live my life. I have to remember—this isn't a dress rehearsal!
- There are many good things to enjoy in spite of this disease. I choose not to let the AS become a dominant part of my life or a dominant part of who I am. I feel fortunate to be able to do that.

Woody Higgins
Southern Pines, NC

Massage Therapy Tips

Massage Therapy Gives New Life to Avid Golfer

Not only were Irvine attorney Ellsworth Vines' dreams of becoming a pro golfer sadly dashed after he was diagnosed with AS in 1967, but he feared that he would not even be able to take to the links again to play his beloved sport.

"I was supposed to have been a professional golfer like my adopted father who basically taught me how to play golf," Mr. Vines remembered to *Spondylitis Plus*, "I was winning local tournaments for a while—and then I couldn't compete; it just got too painful for me to play."

But after having given up golf altogether for more than 25 years, Mr. Vines is now playing again, hoping to soon pare his low-80s handicap down to the 70s. He believes that his feelings of less pain and new abilities for exercise are due to his masseuse, Julie Maul of Orange County, CA, whom he calls "his angel."

"The AS is Still There"

"I went to a body therapy institute and felt so much better after this one woman gave me a massage so I began to request her and I soon learned that everyone was requesting her leaving the other 19 massage therapists with not a lot to do," Mr. Vines explained, who added with a laugh that Ms. Maul has since "gone out on her own to accommodate the enthusiastic clientele."

Mr. Vines says that of course "the AS is still there," mostly in his SI (sacroiliac) joints and lower back. "Sometimes I can't even get out of bed, but since Julie has been working on me, I started playing golf again; handicap-wise, I shot 82 yesterday and I'm hoping to be in the 70s again by the time your story runs."

The AS Client Needs to Educate the Massage Therapist

Ms. Maul warns that the AS client needs to educate their massage therapist on the disease. (See side bar from Bruce Clark, PT) "Massage therapists probably don't know what AS is, so the client should explain what it is.

Ms. Maul went on to explain that the muscles that have to do with the hips are the hip flexors on the front, and the gluteals on the back side and the piriformis, which she says is a muscle in the gluteals region of the lower limb that runs from the base of the spine to the top of the femur "and that's another muscle that is



good to work on if you have low back and hip stiffness." Other muscles that are worked on are the quadratus lumborum and the quads and hamstrings, and according to Ms. Maul, all of these muscles are common AS complaint areas.

It's All Connected

And Mr. Vines, who is in nirvana when on the receiving end of Ms. Maul's massage, describes it this way: "She really works much harder than anyone else at doing the massage and she does it so much more complete; she works around the muscles and around the joints and relieves the pressure on my joints. The muscles are tightened—they feel like knots and when the muscles are tight, the joints don't move freely. I'm not a medical expert, but I know that when I have tight muscles, it pulls on various parts of my joints and pulls them out of alignment and therefore when the muscles are nice and relaxed, and not stressed, the joints don't have additional pressure."

Ms. Maul likens her message technique to playing a guitar: "I passively stretch the muscles through massage. If you have a guitar and a guitar string, you're making the guitar move by pulling

the string on it. The way this is a passive stretch—if your joint can't move, just like a guitar doesn't move, you have to pull the string, so I'm manipulating the muscle around it to stretch the muscle out."

Any way you look at it, it's all sweet music and sweet swings for Mr. Vines who is once again enjoying the game he loves.

Hints from a Massage Therapist

If you find yourself considering massage therapy, Ms. Maul recommends that you first communicate with the therapist about special needs. There are things that can help such as using the correct headrest to accommodate a person with AS—such as using a face cradle since not all therapists have special table with a adjustable headrest. And if you have never received a massage, here are some hints from Ms. Maul on how to receive one:

- Tell the therapist the area of your body that is sore, injured or tense
- Mention all medical conditions besides the AS issues, such as varicose veins, blood pressure problems or recent surgeries
- When the therapist locates the area of pain or tension in the body, consciously try and relax; breathing usually helps that as some people tend to hold their breath
- Be limp like a rag doll so that he/she can move your limbs into various positions; don't try and help and do not work against the massage therapist
- The best way to receive a massage is with the body completely unclothed. "We are all trained to keep the body covered at all times, and we will basically bring out an arm or a leg—so you are covered at all times; we're sensitive to the need for privacy."
- Falling asleep is normal. "We'll wake you up when it's time to turn over or when the massage is over."

Massage Therapy: Is it For You?

I read with interest Mr. Vine's anecdotal report on the effect of massage on his AS. I am tempted to follow his advice if it could get my golf score as quickly into the 70s. I think, however, the experience, positive as it has been, should be put in perspective.

Mr. Vine makes it clear that the magic is perhaps Ms. Maul's unique skills as he says "everyone was requesting her, leaving the other 19 massage therapists with not a lot to do." If massage was the thing that produced the change, might not others be able to achieve similar benefits?

Ankylosing spondylitis is an inflammatory condition, which manifests primarily as pain and loss of joint mobility, particularly in the spine. It is certainly true that muscles, ligaments and other soft tissues are involved, such as muscles in spasm protecting painful joints from excessive motion, ligaments that accommodate with tightness to the loss of motion.

It is important that disease management include anti-inflammatory medication or disease modifying medication when indicated; that management include a regular exercise regimen for mobility, strength, posture, flexibility; that management includes a full educational program so the individual can understand both the disease and the rationale for the treatment interventions. These three aspects are fundamental to good management and in varying degrees have demonstrated validity.

There are a variety of additional things that can be useful, but less predictable. These will vary from individual to individual. These may include massage, acupuncture, baths, wraps, electrical modalities, lotions and potions—the list is long.

In most instances, these secondary interventions are not harmful and can be useful. Perhaps the biggest risk is that of placing too much faith in one of the unproven remedies and in doing so, failing to follow standard regimens; when used as supplementary strategies they can be used in a wiser manner.

Should your massage therapist stray from their specific field, and begin additional interventions such as passive stretching, traction, manipulation etc., you had better act promptly to protect yourself and insist that they stick to their professional boundaries. There can be risk with very deep massage and mobilization, particularly in the neck. Caveat Emptor! The sentence in Mr. Vines' article, "Ms. Maul warns – "Massage therapists probably don't know what AS is." If that is so, then you, the patient, need to ensure that the massage therapist operate strictly within their scope of practice and confine treatment to massage only.

Work with your rheumatologist and other health professionals that they recommend in order that the interventions are both safe and effective; this may include massage.

Bruce Clark
Physical Therapist
Member of the SAA Medical and Scientific Advisory Board

SoundBites in Rheumatology

Continuation of Treatment with Infliximab in Ankylosing Spondylitis: 2-yr Open Follow-up

Objective

To evaluate the continuation and safety of treatment with infliximab in ankylosing spondylitis (AS) over a 2-yr period.

Infliximab (Remicade®) administered on an “as needed” basis over a two-year time period to patients with ankylosing spondylitis, showed what French researchers called “an acceptable safety profile” at the conclusion of their study.

Fifty patients were recruited for the study, all of which were accounted for at its conclusion. Four patients and their doctors felt that the Remicade did not work for them and withdrew from the study. Seven more withdrew due to adverse events; the majority of these patients suffered allergic reactions to the infusion.

Conclusion

This study demonstrates a long-term treatment continuation of infliximab in AS, and shows an acceptable safety profile. It appears that for some patients the disease can be controlled with longer intervals between infusions; these findings warrant further studies.

Rheumatology 2006 45(7):859-862;

Enthesitis (inflammation where ligaments attach to the bone)

It is well known that the first signs of AS are inflammatory in nature, and that the inflammation takes place in body tissues, particularly at the point where ligaments, tendons, or joint capsules attach to the bone. The medical term for these attachment sites is entheses and the inflammatory condition is called enthesopathy or enthesitis.

Enthesitis has long been considered one of the clinical hallmarks of ankylosing spondylitis as well as the related diseases. It most often shows up in the lower limbs rather than in the upper limbs and is most frequently experienced in the heel. The pain, resulting from the enthesitis, can range from mild to severe and disabling. Advances in technology such as the use of ultrasound and magnetic resonance imaging (MRI) now provide us with the ability to confirm the association of enthesitis with all forms of spondyloarthritis. This along with improved treatment options presents potentially important advances in disease management.

*Best Practice & Research Clinical Rheumatology
Volume 20, Issue 3, June 2006, Pages 473-486
Spondyloarthropathies*

Effects of Infliximab Treatment on Lipoprotein Profile in Patients with Rheumatoid Arthritis (RA) and Ankylosing Spondylitis (AS)

Objective

In this study researchers sought to investigate the long-term effects of Infliximab (Remicade ®) therapy in patients with active RA and AS.

The World Health Organization predicts that cardiovascular disease will represent the major cause of morbidity and mortality worldwide before 2010. It has been reported that cardiovascular disease is seen at higher rates in people with RA when compared to the non-affected population. It has also been suggested that active RA is associated with unfavorable lipid profiles* when compared to people with RA in remission. There seems to be some indication that some anti-rheumatic drugs, either alone or in combination with others, may have a positive effect on the lipid profile of people with active RA. Since prior to the study, there had only been short-term studies assessing the effect of TNF- α blocker therapies in people with RA, this study sought to assess the longer-term effect in a large group of people with active RA and active AS.

Results

There were 50 patients with RA and 32 patients with AS included in the study. The results of the study concluded that the long-term effects of infliximab on the lipid profile of the active RA and AS patients was neutral after six months of therapy, since during this time none of the major atherosclerotic risk factors either increased or decreased. Hence, the researchers concluded that the previously reported probable favorable effect of infliximab treatment on cardiovascular morbidity might not be caused by the effects on lipid profile but by some other factors, which have not yet been identified. It was noted that further investigations are needed to define the possible protective mechanisms of infliximab treatment.

*The Journal of Rheumatology 2006; 33:5 Kiortsis, et al:
Infliximab and lipoprotein in RA*

* If you would like to find out more about total cholesterol and HDL cholesterol—sometimes called “good cholesterol” and its effect on health, visit the American Heart Association website:
<http://www.americanheart.org/presenter.jhtml?identifier=4488>

The JANE BRUCKEL RESEARCH FUND

The next phase in SAA's quest to advance research for AS and related disease

Since its inception, SAA has championed the cause of advancing AS research. The Jane Bruckel Research Fund is the next phase in the Quest for the Cure.

By supporting The Jane Bruckel Research Fund, SAA's members and friends can enhance the organization's ability to respond to new research needs as they arise, as well as continue the important projects currently underway.

Your gift today will help to ensure that The Jane Bruckel Research Fund will continue its namesake's efforts to promote the groundbreaking research that will lead to a cure.

For more information please contact:
Susan Jones
 Director of Development
 Email: susan.jones@spondylitis.org
 Phone: 818-981-1616 x 231

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) 937-1484 | jmmkorn@cox.net |
| Long Beach, CA | Barbara Crofut | (562) 421-9698 | crofutgr@netzero.net |
| Long Beach, CA | Frances Tomich | (562) 429-9685 | |
| 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 |
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| Indianapolis, IN | Ken Prather | (260) 637-1705 | pratherken@yahoo.com |
| Lawrence, KS | Karrie Shogren | (785) 832-8738 | shogren@ku.edu |
| Zeeland, MI | Scott May | (616) 610-9130 | smay@wmis.net |
| Great Falls, MT | Jason Jones | (406) 761-1684 | montjon66@hotmail.com |
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| 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

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

- Current information and education
- Speakers who are knowledgeable about spondylitis
- Literature and materials about these diseases
- Confidential, non-judgmental interaction with others
- Opportunities to educate the public
- All of the above
- I would not attend a meeting

OLD POLL RESULTS

Where have you felt the most pain the past month?

| | |
|--------------------------------|-----|
| The lower back | 20% |
| The neck | 19% |
| The mid-back | 14% |
| Hips | 9% |
| Buttocks | 7% |
| Other | 5% |
| Hands, feet, knees | 4% |
| Combination of the above | 22% |

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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.



Jim Stewart in Nashville, TN would like to meet others in his area with spondyloarthritis. If you live in Tennessee and would like to “reach out” to Jim 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

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

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www.spondylitis.org

Save the Date!



**Spondylitis
Association
of America™**

P.O. Box 5872
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JOIN US IN WASHINGTON, D.C.
for an all-day
SAA spondyloarthritis
educational seminar on
SATURDAY, NOVEMBER 11, 2006.

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