Jane Bruckel’s Retirement:
From the Board Room to the Table Tennis Court

Research Abstracts
Presented at the American College of Rheumatology Meeting

My Experience at the Bath Royal National Hospital’s Rehabilitation Course for Ankylosing Spondylitis

Photo by William R. Greenblatt
Just as each person is different, each case of spondyloarthritis is different. Whether it be the disparate ways the disease manifests between the genders, varying age of onset, mild vs. severe or the unique and personal ways that people cope with chronic illness, no two individuals experience the same “spondylitis”.

Treatment options are a prime example. Aside from knowing exercise is key to everyone with spondylitis - and a cornerstone of treatment - the introduction of the TNF-alpha inhibitors in 1998 also improved the lives of so many who had previously been without any improvement from the daily challenges that define the disease. For many, the advent of these medications offered a new lease on life. As we move forward, scientists continue to investigate new therapeutic approaches for ankylosing spondylitis. One of the most promising examples is a monoclonal antibody that blocks a cytokine known as interleukin-17.

At SAA, we make a concerted effort to keep you informed about new medications and research via email through our monthly electronic newsletter, (eSUN) and on the weekly news section of our website (spondylitis.org/press).

But we also recognize that drug therapies, especially those employing the more recently developed biological drugs, are not always the answer. Therefore, SAA is committed to providing education and information in a wide range of areas so that individuals, in conjunction with their doctors, can make informed decisions about which healthcare options to pursue. To this end, alternative or complementary treatments will continue to be explored via interviews and articles in this news magazine, on our website, and through our new Alternative Treatment / Diet Discussion Forum on our message boards (find the forum at http://forums.spondylitis.org).

This is just one of the ways SAA is fulfilling its mission in the field of education. That said, some of the most valuable information comes from your peers in the spondylitis community. Going forward into 2011, we are planning to launch “SAA Connections” an over-arching program that will incorporate all the different ways SAA can help you connect with others who have spondylitis, as well as with doctors and experts who can help. From our nationwide network of support groups to Facebook to our forums to educational seminars, SAA Connections will be a way for you to reach others who understand and who want to help.

Sincerely,

Laurie M. Savage
Executive Director
**READERS’ FORUM**

**SAA’s Open House**

*Editor’s note:* SAA held a local open house brunch at its new offices in Van Nuys, CA on January 29, 2011. Donors, members and guests mixed and mingled with SAA staff, SAA co-founder and former executive director Jane Bruckel, BSN, RN and heard an update on spondylitis research from SAA Medical and Scientific Advisory Board Member Michael Weisman, MD. Below is a letter we received from one of the SAA member attendees.

Dear Laurie and All,

Thank you all so very much for the opportunity to meet with you at the open house. [Another SAA Member] said you were all exceptional humans and you lived up to the billing.

The food was fabulous as was the opportunity to meet some others with spondylitis, and especially to hear from Dr. Weisman.

Love, peace and thank you,

~DIA H., San Louis Obispo, CA

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**A Fond Farewell**

Dear SAA Members & Friends,

I am writing to let you know about some staff transitions taking place at the Spondylitis Association. Sadly, I am leaving SAA; my husband and I are moving back to Texas early next month for family reasons. My last day at SAA will be Thursday, January 27.

Thank you for all of your support and kindness through the years. I feel blessed to have worked at such an outstanding organization and to have served such an amazing community. SAA and the entire spondylitis community will not be far from my heart.

It was a wonderful (almost) 5 years with all of you.

Thank you so much,

~MELISSA VELEZ COELHO

Former Director of Program Services, Spondylitis Association of America

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**LETTERS TO THE EDITOR**

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

We reserve the right to edit for space and clarity.

*Please send letters to:*

laurie.savage@spondylitis.org

Letters to the Editor/SAA

P.O. Box 5872, Sherman Oaks, CA 91413
The American College of Rheumatology’s Annual Scientific Meeting, held each fall, is the premier scientific meeting devoted to the rheumatic diseases. This multi-day meeting draws thousands of rheumatologists and arthritis health professionals from around the world. The leading minds in rheumatic research present the results of their studies to other researchers, clinicians and rheumatology healthcare professionals.

It is at this meeting that the great advances in the field of rheumatic disease are unveiled. SAA has been attending ACR’s Scientific Meeting as an Exhibitor since 1987. Here are a few of the abstracts presented at the American College of Rheumatology Annual Scientific Meeting, November 2010.
Striking Prevalence of Axial Spondyloarthritis in Primary Care Patients with Chronic Low Back Pain

Researchers from the Netherlands set out to determine the prevalence of axial spondyloarthritis (aSpA) in primary care patients with chronic low back pain as classified by the Assessment of Spondyloarthritis International Society (ASAS) criteria. 364 patients (43% male, average of 36.3 yrs) were evaluated. The overall point prevalence of aSpA was 21.5 % using the ASAS criteria, 52 were diagnosed by the MRI criteria with one other SpA feature and 12 were diagnosed by a positive HLA-B27 and two other SpA features. Based on the modified New York criteria they identified 6.6% of which 75% also fulfilled the ASAS criteria. Researchers concluded that the prevalence of aSpA was strikingly high among primary care patients who have chronic low back pain. Determining HLA-B27 and X-ray of sacroiliac joints could help physicians in primary care identify patients that should have accelerated referral to a rheumatologist to start accurate treatment as early as possible.

Increased risk of gastrointestinal (GI) complications in persons with AS

Previous studies have determined that persons who have ankylosing spondylitis (AS) may be at increased risk for GI complications for two reasons. First, GI inflammation is frequently observed in people who have AS. Second, AS symptoms are often treated with non-steroidal anti-inflammatory medications, which can increase the risk for GI ulcers. Researchers from Canada conducted a study to determine the age- and sex-specific risk of GI disorders among people with AS versus people without AS. From a review of a Canadian physician-billing database for 8,616 persons with AS and a 1% random sample of individuals without AS, researchers determined that individuals with AS are at increased risk for many types of GI complications. The risk may be more pronounced among younger individuals. Ulcer-related GI complications were the most common and persons with AS had the highest risk for inflammatory GI diseases.

Clinical characteristics and impact of biologic therapy in uveitis related to AS

Researchers from Canada and Singapore conducted a study to determine the impact of biologic therapy on the incidence of acute anterior uveitis (eye inflammation) and to identify predictors of a uveitis flare. Researchers evaluated 132 AS patients with a history of uveitis (out of 464 AS patients total) and determined that having the HLA-B27 gene marker is a strong predictor of uveitis. In addition, researchers found a high incidence of enthesitis in uveitis patients. They also concluded that biologic therapy reduced the incidence of uveitis.

Metabolic syndrome and spondyloarthritis

Previous research studies have determined that spondyloarthritis may be associated with an increased risk of cardiovascular disease. Metabolic syndrome (MetS) is the name for a group of risk factors that occur together and increase the risk of coronary artery disease, stroke, and type 2 diabetes. Researchers from Italy conducted a study to determine the prevalence of MetS among patients with spondyloarthritis. They enrolled 119 patients in total (73 with psoriatic arthritis; 20 with AS; 15 with undifferentiated spondyloarthritis; 6 with enteropathic spondyloarthritis; and 5 with reactive arthritis). Researchers concluded that MetS is a common finding in spondyloarthritis patients. The prevalence of MetS among this group of spondylitis patients was 36.9 % with the highest prevalence among the enteropathic spondyloarthritis group (50%), followed by psoriatic arthritis (41%), ankylosing spondylitis (35%), undifferentiated spondyloarthritis (26.6%), and reactive arthritis (0%). Higher prevalence was also seen among patients over the age of 60, and it was more frequently seen in male patients (43%) compared to female patients (27.6%).
Response to treatment: undifferentiated spondyloarthritis versus AS and psoriatic arthritis

Researchers from the Netherlands conducted a study to assess whether patients with undifferentiated spondyloarthritis (USpA) are different from AS and psoriatic arthritis (PsA) patients in terms of patient characteristics, disease activity and response to treatment. The study included 40 USpA patients, 74 AS patients, and 45 PsA patients (175 patients total). Researchers concluded that despite the atypical presentation and shorter disease duration, a large majority of USpA patients have high disease activity. When TNF blockade medication was administered to patients with high disease activity, researchers observed a significant and sustained decrease of the disease activity in USpA, which was similar to the response in AS and PsA.

Benefits of membership in spondylitis patient organizations

Researchers in Germany evaluated the differences between AS patients who are members of a patient organization and AS patients who are not members. In total, 1,273 AS patients (1,068 members and 205 non-members) responded to a questionnaire consisting of 82 questions related to demographics, diagnosis, smoking, acquisition of information about the disease, disease activity, mobility, functional status, patient satisfaction, quality of life, treatment and disability to work and educational levels. Researchers concluded that there are numerous benefits associated with membership in an AS patient organization. AS patients who are members feel better informed about AS, have better functional status, a healthier lifestyle, and overall seem to cope better with the disease than non-members.

Pregnancy in Ankylosing Spondylitis and Back Pain

Previous studies of pregnancy in AS have not included a control group in order to account for pregnancy-related effects on general back pain. In this study, researchers evaluated pregnancy in patients with AS against control patients with psoriasis. Nineteen AS patients (with 35 pregnancies) and 33 patient controls (with 77 pregnancies) completed a questionnaire to evaluate their back pain during pregnancy. AS patients experienced significantly more back pain compared to controls in all three trimesters. However, it was noted that, during the first trimester, there were significant improvements in pain and stiffness in AS patients compared to their baseline pre-pregnancy levels. However, in the 2nd and 3rd trimesters AS patients experienced significantly more pain and stiffness. During the first month after pregnancy, AS patients had less pain and stiffness, but their symptoms worsened during the second to sixth month following pregnancy.

Researchers concluded that the improvement in back pain and stiffness during the 1st trimester could be related to human chorionic gonadotropin (HCG) hormone in the 1st trimester of pregnancy. Previous hormonal reports have found that HCG possesses significant analgesic effects. The worsening of symptoms in the 2nd and 3rd trimesters was seen in both AS and controls and likely reflects biomechanical loading of the low back in later stages of pregnancy. AS patients appear to return to baseline levels of pain and stiffness post partum, which suggests that pregnancy does not substantially aggravate disease activity in AS.
Newly diagnosed: gender differences and delay in diagnosis of AS

Gender differences have been demonstrated in patients with advanced AS, however there are no studies evaluating this in patients who are recently diagnosed with AS. Researchers from Israel sought to characterize a group of patients with recently diagnosed AS with emphasis on gender differences and factors leading to delay in diagnosis. Seventy-nine men and 72 women with AS were enrolled in the study. Both genders had similar age of onset of disease related symptoms, as well as similar delay time to diagnosis, follow-up duration and frequency of anti-TNF treatment. Inflammatory back pain as the first symptoms was report more often by men. Women reported significantly more frequent lower abdominal or pelvic pain, heel pain, and widespread pain during the course of disease activity. There were no gender-related differences in incidence of uveitis, dactylitis, or peripheral joint involvement. Women constituted almost 50% of all recently diagnosed patients with AS, with CT or MRI studies more frequently used for their diagnosis. Gender-related differences were demonstrated in both disease presentations and burden. Widespread pain in women was frequently reported, and it was related to significant delay in diagnosis versus female AS patients who did not have widespread pain.

Spondyloarthritis and first degree relatives

Previous studies have shown increased frequency of spondyloarthritis (SpA) related manifestations in first degree relatives of patients with AS. Researchers from the US developed and validated a self-administered tool to evaluate the presence of SpA symptoms in first degree relatives of AS patients. Ninety one first degree relatives were enrolled; this consisted of 36 parents, 28 siblings, and 27 children. Researchers confirmed inflammatory back pain in 27 relatives, AS in 10, Achilles’ tendonitis in 25, peripheral arthritis due to SpA in 7, uveitis (eye inflammation) in 6, psoriasis in 4, and reactive arthritis in 2 relatives. No case of inflammatory bowel disease was reported. The findings suggest that the developed questionnaire captures SpA manifestations including AS with adequate diagnosis accuracy and raise the possibility of using the questionnaire as a screening tool for SpA manifestations in first degree relatives of AS patients.

Urolithiasis (bladder stones) in ankylosing spondylitis

Since urolithiasis (bladder stones) represents a tendency for calcium build up and calcification, researchers from Singapore and Canada wanted to determine if this propensity might influence the bone formation in AS. After enrolling 504 AS patients, they determined that 7.5% had a history of bladder stones. When they compared the group who had a history of bladder stones against a control group of AS patients who had no history of bladder stones, they determined no difference in the incidence of bladder stones in terms of gender, ethnic group, HLA-B27 status, smoking history or alcohol consumption. However, those with a history of bladder stones were more likely to have more functional disability. They concluded that there is no acceleration of syndesmophyte (bony growth) formation or spinal fusion associated with bladder stones in AS but the unexpected functional disability should be noted.
Retirement has been anything but quiet for Jane Bruckel. The co-founder of the Spondylitis Association of America has spent her retirement years traveling, bird watching, fundraising... and playing competitive table tennis.

Bruckel’s retirement goal was to get physically fit, but she was not sure how to reach that goal. She tried line dancing, but that didn’t take. Then, one day, she saw people playing ping-pong and she knew she had found her post-retirement calling.

“I loved playing ping-pong as a kid,” says Bruckel, “and I was very athletic before getting AS [ankylosing spondylitis], but I never thought I would play a competitive sport again.”

But play she has over the past four years, for up to 18 hours a week. Bruckel plays in clubs all over the Greater Los Angeles area as part of the Los Angeles Table Tennis Federation, where she is the captain of the Orange Crush team. The LATTF is a nonprofit organization made up of table tennis clubs in the Los Angeles area, with the goal of boosting table tennis participation and competitive opportunities for table tennis players in Southern California.

Playing at this level, Bruckel says, would not have been possible before the advent of anti-TNF drugs, which block the action of tumor necrosis factor, the protein that causes the inflammation associated with AS and other autoimmune disorders. These drugs now give Bruckel, whose spine is fused due to severe AS, the freedom to pursue her competitive dreams.

“I was very athletic before getting AS [ankylosing spondylitis], but I never thought I would play a competitive sport again.”
In 2009, in fact, Bruckel played in 10 singles events at the U.S. National Table Tennis Championship in Las Vegas, where, she says, she “won some and lost more.” Her primary coach, Gao Jun, won the women’s singles title, her ninth championship title at the Nationals. Because of a stress fracture, Bruckel was unable to participate in this year’s competition.

Gao, a member of the USA Table Tennis Hall of Fame, then invited Bruckel to be her doubles partner in a national seniors tournament in June 2010, where they took third in their division. Gao, who is only 40 but qualifies as a senior, won the overall singles title at the tournament.

“I’m still a low-level player,” says Bruckel, “so you can imagine what an honor and privilege it was when Gao invited me to be her doubles partner. After all, she’s the U.S. Nationals champion, and she won an Olympic medal in doubles for China. I was very nervous because I didn’t want to cause us to lose in the first round. But, we advanced three times and ended up taking third. It was the most fun and exciting day of my retirement!”

Bruckel and Gao are planning to partner again in the tournament next June.

Since retiring, Bruckel has not limited her activity to the table tennis court. An avid bird watcher, she and a friend have been making annual bird-watching treks around the country since 2006. One year they bird watched along the Rio Grande River in Texas; another year, they spent time on the Oregon tundra, watching winter birds and bald eagles.

And, she and her husband Harry, avid travelers prior to and during her SAA years, continue to traverse the world, visiting Costa Rica and the Galapagos Islands off the coast of Ecuador, among other exotic destinations.

Her heart, however, is never far from the Spondylitis Association of America. She and Harry serve as honorary board members and are involved in fundraising activities for the organization. Because of her vast institutional knowledge, she is currently working on a project to gather photographs and documents that capture key moments in SAA history. The result will be framed in the SAA offices in Van Nuys, California.

“Wow, we’ve really reached across the world.”

Four years after retiring, Bruckel has also had time to reflect on her 23 years at the helm of the SAA and what the organization has meant to spondylitis patients around the world.

“I never visualized the SAA as such a well-established, national nonprofit organization,” she says, “one that is widely recognized by the National Institutes of Health and throughout the rheumatology community. We put spondylitis on the map in the United States and gave the disease recognition when it had none.”

From its modest beginnings in her small California home, the Spondylitis Association of America today is the only nonprofit organization in the United States that dedicates 100 percent of its resources to improving the lives of the spondylitis community—through education, research and support.

“We had no thoughts then of White House visits or glittering international conferences, no plans for exciting multimillion-dollar research programs and a unique partnership with the National Institutes of Health, no dreams of groundbreaking genetic studies to solve the mystery, which, it turned out, had plagued mankind since the days of the Pharaohs,” she wrote in Spondylitis Plus when she retired in 2006.

In the mid-1980s, Bruckel was a pioneer for the spondylitis community. Back in those pre-Internet days, she says, AS patients were in “total isolation,” with no printed material on the disease—not even a little pamphlet, she adds—and no way for patients with AS to connect with one another.

From day one, Bruckel says, the organizers of the SAA knew they were making a difference. Hundreds of letters poured in from across the country, offering positive feedback. After publishing Straight Talk on Spondylitis, the most comprehensive resource available to help people understand and manage spondylitis and related diseases, Bruckel says she received a letter from an orthopedist in Japan who wanted to translate and distribute the book in Japan. “We realized, wow, we’ve really reached across the world,” she remembers.

As a result of the organization’s work, physicians and patients are now better educated about spondylitis, and the disease is more widely recognized than it has ever been in the medical community. But, as Bruckel said in her 2006 Spondylitis Plus coda: “There is still a long road ahead.”

Bruckel says that, looking ahead another 23 years, she hopes that the SAA “won’t be needed, that a cure will be found and prevention strategies put in place.” In the meantime, the Spondylitis Association of America will keep “working at it,” she says—and Jane Bruckel will continue her quest on the table tennis courts.
SAA has been blessed with an enthusiastic core of dedicated volunteers who have taken on projects ranging from fundraising and spreading awareness to providing support and advocating on behalf of the community.

Whether it be organizing benefit concerts, hosting educational fundraising dinners, designating a portion of their auction proceeds to benefit the organization or naming SAA as a beneficiary of their wedding or other event -- large or small -- SAA’s Volunteer Fundraisers go above and beyond the call to provide financial support and spread awareness for the betterment of the spondylitis community as a whole.

For that, they have our sincerest thanks. For more information about becoming a volunteer fundraiser for SAA, please contact Robin Kindrick at 800-777-8189 or by email at robin.kindrick@spondylitis.org.

But not all volunteer activities are about raising money. SAA’s Support Group Leaders, Peer Mentors, Advocates and our growing number of social media supporters take the time from their busy lives to make a direct, positive impact on the lives of others affected by spondylitis. To become involved in these or any of SAA’s other programs, contact Elin Aslanyan at 800-777-8189 or at elin.aslanyan@spondylitis.org.

**Can One Volunteer Make a Difference...?**

*We Think So...*

The Spondylitis Association of America is an organization conceived, launched and grown by volunteers.

As a young nurse she endured years of severe back pain and no one knew why. When the diagnosis finally came, it brought more questions than answers -- Ankylosing Spondylitis. Her nursing text gave the disease one paragraph.

But there was not a single patient resource available for the handful of fellow AS patients she gathered together in her living room. Not a single pamphlet or fact sheet written specifically with the patient in mind.

Jane Bruckel was determined to change that. Twenty-eight years ago she volunteered her time, money and dedication to co-found the Spondylitis Association of America and her visionary leadership helped forge the SAA into the professional organization that we now know.

Today, SAA publishes thousands of educational materials for patients and physicians alike, holds local and national symposiums and raises money for the most challenging area of all -- AS research -- which has uncovered groundbreaking new discoveries that bring us closer to the cure.

Thanks to the commitment of one woman, supported by a small group of fellow volunteers, thousands of spondylitis patients now live more active, more rewarding lives.

Never doubt that a small group of committed people can change the world. Indeed, it is the only thing that ever has.-- Margaret Mead
In 1996, starting out in my new job as director of program services for the SAA, it quickly became apparent to me that our staff of three, including Jane Bruckel, SAA’s co-founder, was trying to meet the needs of a much underserved population. There were so many gaps in all areas that ranged from lack of interest in spondylitis within the medical community to grossly delayed diagnosis, especially in women with obvious classic symptoms associated with the disease. All this indicated much work ahead. The good news was that we were supported by a talented group of volunteers, including some of the initial support group leaders, all across the US. Though the group was small, the passion was great. And we certainly needed passion in those early days of getting the NASC Family Genetic Study underway, building our first website and expanding patient services. The challenges were great and we threw ourselves into the fray with gusto!

At that time, one of my responsibilities was to answer the 800 line, long before the Internet really took off. Consequently, I had the opportunity to learn a great deal about human nature and specifically about courage in the face of adversity. Little did I know that a personal transformation soon would occur as I met many of you in person and on the telephone. Serving our population quickly became my passion.

Today, the SAA has grown into its shoes with a full-time staff of nine. Working with Dr. John Reveille and colleagues, and with your support, the genetic determinants of these conditions have been exposed. There are improved medicines, diagnosis is occurring more quickly, we have a better understanding of the overall management of spondylitis, and there are many more program services available today than ever before. Yet, much has still to be accomplished. There are challenges still to be met before we will fully understand what triggers this group of diseases. Though researchers are encouraged, the cure is still the goal.

In 2009, SAA established a planned giving program. We launched the Quest Legacy Society to ensure the necessary funds to support research and program services for future generations affected by spondylitis. The word “Quest,” in literature and in mythology, conjures up “significance-laden journeys.” This will be ours -- toward a better future for those affected by spondylitis.

That is why I am proud to be a charter member of the Quest Legacy Society. My special thanks to all of you who have planned an SAA gift in perpetuity to support program services and research toward the cure.

If you haven’t yet designated an estate gift, won’t you consider joining us today? Your generosity will ensure that future generations, unlike those who have gone before, are not underserved.

For more information on becoming a member of the Quest Legacy Society and how planned giving can work for you, please go to www.spondylitis.org/quest or contact Susan L. Jones, Director of Development and Planned Giving at 800-777-8189, ext. 231 or at susan.jones@spondylitis.org.
The questions and answers below are transcribed from the Spondylitis Educational Seminar held in Atlanta, GA in November. We are grateful to our keynote speaker, Lianne Gensler, MD for taking the time to answer attendees’ questions.

**Q:** Is there any test that can tell me if I am in remission?

**A:** You can tell me if you’re in remission. Do you feel really well or is the inflammation ongoing? If there’s no inflammation, then you are probably in remission. How do we know if there’s inflammation? Are you having stiffness in the morning when you wake up? Are you waking up in the middle of the night with pain that gets better with activity? Those are typical symptoms of inflammatory back pain and ongoing inflammation. Are your SED rate and CRP, markers of inflammation, still elevated? Really, at the end of the day, it’s the patient that knows whether they are in remission or not.

That said, it’s harder to determine when people have fusion of the spine because then they might have ongoing pain from damage to joints as opposed to inflammation.

**Q:** I’ve switched from Enbrel (entanercept) to Humira (adalimumab). How do we know when it’s time to switch to a different TNF-a blocker?

**A:** It depends on what the response is, and it depends on the reason for the switch. If the reason for the switch is because there wasn’t a response to etanercept and you haven’t responded to adalimumab depending on how long it’s been, it’s reasonable to switch to a different TNF-alpha inhibitor. We definitely have data to say that people can respond to one and not another.

I always tell patients that there is no miracle drug. There’s no quick fix, and so considering other complementary treatments, for example, physical therapy, taking an NSAID, etc. may be helpful as well. In other words, switch around the little things before thinking about changing big drugs.

**Q:** If you stop taking a TNF and then you start taking it again, is there evidence to show that it’s less efficacious when you start taking it the second time?

**A:** It depends on which one you were on. If you were on Remicade (infliximab), it’s probably not a good idea to stop and start because it’s more likely that you’ll develop antibodies towards it. There is no evidence that if you stop and start entanercept, for example, it’s going to work less well, but we haven’t studied it. All we’ve studied is treating it continuously.

**Q:** Where would you say is the most exciting research coming out of right now worldwide in regard to reversing the disease?

**A:** We are now collaborating with many other centers, both across the country and across the world on a big genetic project. That’s going to increase the power and the diversity of the patients, not only that I enrolled in the study, but those enrolled at all the centers. SAA is very, very involved in making sure that this moves forward and that we are collaborating with the right people.

**Q:** I really appreciate you saying “stay active” but what do you do when you are in so much pain you can’t move?

**A:** My general recommendation is start low and go slow. Even if you remember being a marathon runner, you’re not going to go back to that right away. Set very small goals for
yourself, and that might mean walking to the mailbox initially, and then eventually getting to halfway down the block, and adding a little bit at a time.

Q: Do you ever prescribe steroids like prednisone, and what are your recommendations?

A: There is no evidence that corticosteroids like prednisone help ankylosing spondylitis, and the doses that you need to use to really decrease inflammation are not worth the benefit. Remember that those drugs also increase osteoporosis. When you have someone who is already at risk for osteoporosis and then you use really high doses of prednisone, the risk far outweighs the benefit, so no, I do not use prednisone. Now, if you have terrible uveitis that is not responding to topicals and injections, sometimes they’ll use prednisone for that purpose and for IBD sometimes they’ll use prednisone; but for the sacroiliitis of AS, no.

Q: Can you talk a little bit about sleep disruption in AS?

A: People with early disease or active disease often wake up the second part of the night and have pain and stiffness, so they have to move around before they can get back to sleep. I treat those patients with a long-acting NSAID. I’ll recommend that my patients take their non-steroidal at night before they go to bed, then it will be in their system at 3:00 or 4:00 in the morning, so they are not waking up because of pain.

If you are fully fused and you just can’t get comfortable, that’s different. Sometimes using supportive pillows will help. I know a lot of people will have some reduction in pain if they put a pillow between their knees, for example. It just straightens out the spine. Using the right pillow for your neck is important, too, especially if you’ve got neck fusion.

There is no evidence that mattresses make a difference. So don’t go out and spend a lot of money on a new mattress. There is one weak paper that showed maybe a moderate firm mattress is better than a soft mattress in patients with back pain, but it was not specific to AS at all.

It should be noted that patients with any chronic disease are at risk for depression in general. So, if that’s part of what’s contributing to sleep disturbance then it’s important to get it treated, as well.

About Lianne Gensler, MD

Dr. Gensler is Assistant Clinical Professor of Medicine and Director of the Ankylosing Spondylitis Clinic at the University of California in San Francisco. Her primary research interest is in the area of Ankylosing Spondylitis. She is currently enrolling patients with AS in a natural history cohort. Her aims are to better understand why some patients progress to have more radiographic disease severity and which patients with axial undifferentiated spondyloarthritis go on to develop ankylosing spondylitis. She is also collaborating with other scientists to develop better biomarkers for disease activity.

Disclaimer: This article is for informational purposes only and is not a substitute for treatment. Please consult your physician.
I was diagnosed with AS in my 30s while living in the US. I tried adalimumab (trade name Humira™) unsuccessfully and then etanercept (trade name Enbrel™) when it first became available. Etanercept provided a lot of relief to the pain in my thighs and spine. However, now in my 50s I questioned if the etanercept was still as effective. I had increased pain in my spine and sacrum area, and frequent leg and neck pain had returned. As an art teacher I often work 12 hour days. I had a forty-minute commute each way and a 20-minute lunch break if lucky. My after work situation was similar to most women – cooking, household chores, planning lessons for next day, etc. I was exhausted and feeling in a constant flare. I could not sleep because of the pain, and I hurt all day. Something had to change.

During this time, I read AS News, a news magazine by the National Ankylosing Spondylitis Society (NASS) and about the research generated from Bath, UK. Upon further investigation, I learned about a course specifically for AS patients. So, this summer I went to the Royal National Hospital for Rheumatic Diseases in Bath, England to participate in a rehabilitation course for AS.

**Initial Visit to the UK**
They offered three course levels – fast, moderate and slow, depending on the consultant’s recommendation. There was also a doctor who would see AS patients privately and I immediately contacted his secretary to see if I could get an appointment. I met with Dr. Raj Sengupta and had a one hour consultation. I was immediately hopeful; here was someone who was interested in helping me and took time to go over my whole history. I had to pay privately as I had been out of the UK for over 20 years and could not get treatment through the N.H.S. (National Health Service). By this time, I was happy to pay. I was at the point that I was going to give up my teaching job because I could no longer function physically or mentally.

Following the visit to Dr Sengupta, it was suggested that I attend the Fast Course for AS patients at Bath Hospital. About this time, I was diagnosed with Fibromyalgia and saw almost instant results from duloxetine (brand name Cymbalta™). It felt like another layer of pain was sloughed from my body. Now that I had medications that were helping my AS and Fibromyalgia symptoms, I felt ready to tackle this course.

**The Journey to the UK**
In July, my husband and I celebrated our 32nd Anniversary by flying to England and visiting family. On July 25, my husband saw me settled into an apartment for program participants, which was literally next door to the hospital in Bath.

After my initial introduction to my apartment buddies, Kathy and Rosalind, I felt very assured. Both women had been through the course before and were able to put me at ease. They explained that they had learned so much from the course and that I could expect it to be a life changing experience.

**The Start of the Course**
Together we went over to the “Body Shop” – the physical therapy room where we would learn over the next two weeks how to manage our bodies and minds through exercise, education and a multitude of other strategies.

First, we met the rest of the group (eight in all) and one of the lead physiotherapists, Ingrid. The goals of the program were laid out, which were to improve mobility, maintain correct posture, increase muscular strength and to educate us about all aspects of the condition.
We met individually with Ingrid to answer questionnaires about our current conditions, medical history and what we hoped to achieve during the course. Following the interview, the therapist measured us for flexibility with various instruments to determine our flexibility in neck, spine, side bend and leg spread.

It was clear that even though we worked as a group, the treatment and approach was to be individualized. This was not just a visit to a doctor where you are sent home with medications -- this was a combination of exercises, education and support.

The First Week
On Monday, we began exercises. Each exercise was explained – which tendon or ligament was being targeted and how the exercise could help strengthen and maintain motion for the future. One of the biggest surprises was that the exercises could not only help maintain motion and help short term, but that they could help long term, for example, stooping could be reduced.

After the floor exercises, we went to the hydrotherapy pool. At 4:30, we were done for the day, free to go around Bath or, in my case, to doze, on the bed for a few hours.

On Tuesday, we were introduced to the machine exercises. Again, the benefits of each exercise were explained. We worked for about 10 minutes on each of several machines including the treadmill, rowing machine and bikes. Our goal was to use our muscles, and in my case tendons and ligaments, so that we strengthened them, improved balance, and increased our ability to maintain activity so that we can keep mobile and flexible. I now had an all over feeling of ease of movement, feeling more fluid and less stiff.

"I could not sleep because of the pain, and I hurt all day. Something had to change."

We then met with our consultants individually for 5-15 minutes depending on personal history or need. The consultants went over blood tests, concerns we had, medications and any further treatments that we might need. If you were English, some of the treatments could be addressed right away in the hospital as those patients had National Health Insurance.

Each day there was a session planned. One session was about x-rays; we learned how to read a normal x-ray vs. an x-ray showing AS features. We had two group sessions with Peter, a physical therapist, who described how the tendons and ligaments are affected by AS and noted the exercises that would be appropriate for those areas. We also had two sessions with the podiatrist, Louise. Using “Skelly the skeleton” she showed us how the feet were affected by AS and made individual baselines for our feet. As about half the group had foot concerns, she showed us a few simple exercises. Recommendations were then made for visits to podiatrists or specialists for further treatments.

We also met with Lisa, an occupational therapist, who gave us suggestions on how to improve daily function, remain independent and stay positive. Lisa explained that maintaining better posture would lead to less stress on the ligaments and thus wear and tear on the bones. She also went over the correct sleeping postures and aides,
car supplements and the need to pace journeys by taking frequent rest stops. Walking posture should have shoulders down and relaxed abdominals in. Lying down we can position a pillow between the knees while lying on the back or side. In the car, relax with shoulders down, pace the journey and purchase mirrors that are larger or add on mirrors so that you can see properly.

**Week Two**

We continued with our daily lessons and our topic sessions continued. We had a brief group visit with a pharmacist who discussed COX2 inhibitors, NSAIDs, simple but effective painkillers such as acetaminophen and TNF-alpha blockers. She indicated that the TNF-alpha blockers work on the symptoms of AS, but have not been shown to stop the progression of the disease as hoped.

The lectures about bone and osteoporosis were particularly helpful for me. We were reminded that bones are living tissue with a rich blood supply, so that bones are affected by many things. We were apprised of the fact that there are cycles of rebuilding about every 7 years. Exercise helps the blood circulate and increases cell ability. The suggested exercise schedule is three to five times a week, for 30 minutes.

The goal for the session about pain was to learn coping skills. We discussed the two types of pain: chronic pain (any pain longer than 2 months) and acute pain. The difference between the two types of pain and the messages sent to the brain were explained. In our case, the chronic pain affects our mood and releases the hormones that make us feel rotten, too. The circle of pain (the effect on muscles, spasms, increase in blood pressure and nerve receptors, etc) was explained; the effects lead to frustration, a sense of isolation, and depression, which in turn leads to more pain. The goal is to eliminate inflammation which stops the damage and fusion.

To prevent the circle of pain, we need to keep motivated with our exercises and coping strategies. In effect, we need to look at our daily activity in relation to its measurability and achievability. This is an area that I particularly needed to work on. Suggestions were to reduce responsibilities, give rewards to oneself, set goals, have training buddies, remember the visual effects of AS (imagine oneself with a stoop), join a gym and spend time with friends. Some coping mechanisms include breathing, stretching, swimming, reflexology, meditation, massage, relaxation and talking to others with AS.

“*This was not just a visit to a doctor where you are sent home with medications -- this was a combination of exercises, education and support.*”

**Today**

I have joined a wellness center and I work on the same machinery three to five times a week for 40-50 minutes. I also swim for 10-20 minutes. I do my stretches daily but not all of them. Have I changed my lifestyle? Yes, I have had to stop trying to be superwoman and have hired someone to clean floors and bathrooms, and my husband is firm in his inclusion in the general running of the house. At work, I leave on time, no more 12-hour days, but I still have to cope with the lack of breaks and proper seating, etc. due to school budgets and lack of the government programs that are available in the UK.

**What Have I Achieved?**

A year ago, I was ready to stop work and give in. After this course, I realized that I could make changes and move better if I exercised, rethought my life and made adjustments that made sense. I do have bad days but a lot more good ones. Because I am in less pain and am more flexible, I can join after school activities, visit friends and go out at weekends, something I could not do before. I am well enough to exercise and work out.

The final measurements showed impressive changes for me. Pre-course my BASDAI was 1.0, BASFI 2.4, and BASMI was 5.2. Post-course my BASDAI was 4.6, BASFI 4.4, and BASMI 3.2. My flexibility had increased by 38%, and I am delighted. I not only feel better physically, but I can move like a normal person again.

The AS course at Bath hospital is a course that educates. It teaches about making changes, breaking the cycle and pacing. I now have a list of exercises for floor, equipment, and pool that I know are relevant to AS and my condition. I work on my posture daily with exercises that fit easily into my work-day. I also have new friends. Before this course, I had not met anyone with ankylosing spondylitis. Now I have some life-long friends that I communicate with via e-mail.
Thank you to all the people at the Bath hospital, in particular Dr. Sengupta and his secretary who answered so many questions long distance. Thank you to Ingrid, Peter and Lisa who willed us to do well. Thank you to my doctors who have helped me through the pain and encouraged me through the process. Thank you to my patient husband and family and friends in America and new friends in the UK who listened and did not give up on me even when I gave up on myself. I would also like to thank Stephanie for her help with this article. And finally, thank you to Kathy and Rosalind—yes, it HAS been a life and wellness changing experience! ~Helen Carr
The medical terms that describe symptoms, medications and more when reading or talking about ankylosing spondylitis and related diseases can be confusing. Here are some definitions of terms used in this issue of *Spondylitis Plus*:

**Axial Spondyloarthritis**
Axial spondyloarthritis is a more recently used term for inflammatory arthritis affecting the spine. Physicians can make a diagnosis of axial spondyloarthritis in the absence of radiographic (x-ray) sacroiliitis, which is traditionally used to diagnose ankylosing spondylitis.

**Bath Ankylosing Spondylitis Disease Activity Index (BASDAI)**
The Bath Ankylosing Spondylitis Disease Activity Index is a self-assessment tool that was created to determine disease activity and to rate effectiveness of treatment for those with AS. The BASDAI consists of 6 questions related to the major symptoms of AS, which are rated on a one through 10 scale (one being no problem and 10 being the worst problem). The resulting 0 to 50 score (two questions are averaged to provide 1 of the 5 scores) is divided by 5 to give a final 0 – 10 BASDAI score. Scores of 4 or greater suggest suboptimal control of disease, and patients with scores of 4 or greater are usually good candidates to change their medical therapy.

**Bath Ankylosing Spondylitis Metrology Index (BASMI)**
The Bath Ankylosing Spondylitis Metrology Index consists of 5 clinical measurements to assess the spinal mobility in ankylosing spondylitis patients. These measurements include cervical rotation (average of L & R); tragus (ear) to wall (average of L & R); lumbar side flexion (average of L & R); Lumbar flexion (modified Schober’s test); and intermalleolar distance (distance between the ankles’ bony protrusions). Scores are calculated using the BASMI scoring table, which results in a number out of 10. The higher the BASMI score the more severe the patient’s limitation of movement is due to their AS.

**Bath Ankylosing Spondylitis Functional Index (BASFI)**
The BASFI is a set of 10 questions designed to determine the degree of functional limitation in those with AS. The ten questions were chosen with input from patients with AS. The first 8 questions consider activities related to functional anatomy. The final 2 questions assess the patients’ ability to cope with everyday life. A visual analogue scale (with 0 being “easy” and 10 “impossible) is used to answer the questions on the test. The mean of the ten scales gives the BASFI score – a value between 0 and 10, with a higher score correlating to more functional limitation.

**Brand Name**
The brand name (trademark) of a drug is coined by the manufacturer in agreement with the regulating agencies, unlike the generic name which indicates its active ingredients. For example, celecoxib is the generic name for the drug whose brand name is Celebrex. The brand name starts with a capital letter but the generic name does not. Several brand name drugs can have the same generic name if they contain the same active ingredient. Thus, Motrin and Advil are both brand names for the generic drug ibuprofen.
SAA-Sponsored Educational Support Groups

If you’d like to find out more about support groups or for a complete list of groups and meeting dates, visit our website at:
http://www.spondylitis.org/patient_resources/

You can also contact Elin Aslanyan here at SAA by calling 1-800-777-8189 ext. 222 or by email at elin.aslanyan@spondylitis.org for more information.

Recent Meeting Highlights:

Where: Irvine, CA
When: Saturday, November 20, 2010
Speakers: William Shiel, MD, FACP, FACR & Hernan Castro-Rueda, MD

Where: New York, NY
When: Wednesday, September 22, 2010
New Group - First Meeting!
Introductions and Round Table Discussions

Where: Woodlands, TX
When: Saturday, September 11, 2010
Dr. Hyun Jong Kim spoke about the Acupuncture Health Center in The Woodlands
S.M.A.R.T. is a safe, secure and convenient way to put more of your money to work advancing the spondylitis community’s shared mission. Just specify a monthly amount and SAA will automatically deduct the contribution from your credit card. At the end of the year, we’ll send you a summary of your giving and a tax receipt. Your dependable monthly gift of $100, $50, $25, $15 or even $10 will boost the impact of your SAA membership gift many times over.

To sign up for the S.M.A.R.T. Givers Program, go to www.spondylitis.org/smart or contact Helene Hart at 800-777-8189, ext. 229 or at hhart@spondylitis.org