Q&A On Spondyloarthritis With The Hospital For Special Surgery

Magnetic Imaging Workshop in Spondyloarthritis (SpA)
ON POINT

Dear Readers,

As the sun sets on calendar year 2014, we look forward to what the New Year will bring. We anticipate bright moments of joy; successes; always challenges; ongoing relationship building with the individuals who matter most to us, you. All the while we promise to continue to keep our eye on the ball and our nose to the grindstone as we serve the spondyloarthritis community (AxSpA).

We thank those who have worked alongside SAA staff, board and support group leadership this concluding year in serving our Mission. We thank the generous donors and supporters, including industry, and individual fundraisers without whom our program services would not be possible. Not forgetting those in social media sharing the tweets, posting on Facebook, joining the conversations on our forums and putting their faces of AS out there for all to see.

All of these things help to spread awareness of this oft’ ignored group of diseases that can leave the devastation of emotional and physical pain in its wake. Last but certainly not least, let us acknowledge the tireless work of those medical professionals dedicated to AxSpA who juggle the care of patients, and the rigors of research which for the most part is purely volunteer and unremunerated in traditional terms. These research clinicians are there for you and we applaud them for their unrelenting dedicated service.

Thank you, all.

Onward and upward. Exciting new challenges and opportunities are just around the corner and we boldly begin calendar 2015.

Please accept my personal warmest regards for your support and friendship throughout 2014 and in advance for the year to come.

Laurie M. Savage
Executive Director
Thoughts From A Doctor #1
I am a physician (ER doctor) myself and it sometimes feels like there is a little too much “doctor bashing” going on in spondylitis support sites. We do our utmost to diagnose and advise people as best we can. In addition, conditions like ankylosing spondylitis (AS) by their nature can require a certain amount of time to diagnose as it is not until one takes into account a range of symptoms that have occurred over a period of time that things become clear.

We can’t immediately run pathology and scan every person that presents with back pain - this would not be in either the individual’s or the public’s best interest. However, I do agree that many doctors need more education regarding the presentation of AS and related conditions.

For example, I did not recognise my own AS for many years - partly through denial and stubbornness (I kept thinking pilates and yoga will fix this!), but largely because I was not aware of how differently AS can present in adolescence and in women compared to men (in medical school it was EXTREMELY briefly mentioned, and the take home message was that it was a condition mostly affecting men, can progress to a “bamboo spine” and is associated with iritis).

Thus, I am incredibly grateful for, and supportive of, the work of SAA and thank you all for your efforts in education and raising funds for research.

Thank you again. Best regards,
~Dr. Cate Kingham,
Sawtell, NSW, Australia.

Thoughts From A Doctor #2
I wanted to thank you for taking the time to teach me about recognizing findings of sacroiliacs. Since then I have been diagnosing cases, often also with inflammatory bowel disease at least weekly. I am humbled to think how many of these cases have been missed in the past. I saw an unfortunate case of sacroiliitis, inflammatory bowel disease and a pancreatic carcinoma in a 37 year old woman this week. I have been surprised at the number of patients who have been undiagnosed or erroneously diagnosed. This is definitely an area that radiologists can make a difference in patient care.

Thank you again! You really made a difference in the quality of my work.
~A Radiologist

Editor’s Note: This was an email forwarded to us from a rheumatologist we work closely with (we de-identified the sender and recipient on request). It was received a few weeks after we held a workshop for rheumatologists and radiologists called, “Magnetic Imaging Workshop in Spondyloarthritis (SpA).”

The purpose of this certified continuing medical education program was to educate radiologists and rheumatologists in spondyloarthritis imaging and to promote earlier diagnosis in SpA. You can read more about this groundbreaking program on page 10.
Q&A
On Spondyloarthritis With
The Hospital For
Special Surgery
LIVING WITH SPONDYLOARTHRITIS

Editor’s Note: Earlier this year the prestigious Hospital for Special Surgery in NY invited SAA to submit topic suggestions & questions for a piece they wished to write on spondyloarthritis. We brought the opportunity to our community via our Social Media channels, and received a plethora of responses. The following Q & A is the outcome of this partnership. We thank the Hospital for Special Surgery, rheumatologists Dr. Susan Goodman (part one) and Dr. Dalit Ashany (part two), and YOU – our community for taking part in this unique collaboration. Reprinted with permission.

Part One With Dr. Susan Goodman:

Q1. Patients are often dismissed for years and simply live in pain as blood work and x-rays can often all come back normal in Spondyloarthritis, and it can be an ‘invisible disease’ for a long time. How should a good primary care physician go about screening for Spondyloarthritis in their patients with chronic back/joint pain? And what can the patient do to better advocate for themselves when living with an undiagnosed illness?

Dr. Goodman: Due to the scope of the problem, screening patients with low back pain (LBP) is a challenge for primary care physicians. About 25% of those between the ages of 30 and 50 report LBP, which is the most common cause of disability in those aged 45 or younger, yet 50% of those with LBP are better at one week, and 90% in 8 weeks. However, spondyloarthropathy, manifested by inflammatory back pain, may be as prevalent as rheumatoid arthritis, yet the average delay in diagnosis is 9 years, in part due to the lag in x-ray manifestations of sacroiliitis needed for diagnosis. Since the problem of back pain is so common, radiographic sacroiliitis may not be apparent on plain x-rays and MRI evaluations on all patients with LBP is impractical, primary care MDs should screen by identifying the features of inflammatory back pain. These include onset below age 40, insidious onset, improvement with exercise, no improvement with rest, and night pain. Improvement with NSAIDs (nonsteroidal anti-inflammatory drugs) is another useful feature. When these features of inflammatory back pain are present, the patient may be either referred to a rheumatologist for evaluation, or further screened by testing for the genetic marker for spondyloarthropathy, HLA-B27, which is the key lab marker for spondyloarthropathy. Using the strategy of screening by history with referral of all patients with inflammatory back pain, with or without a positive HLA-B27, or with sacroilitis on imaging, early diagnosis can be made.

Q2. Could you address the ways Ankylosing Spondylitis can present in women that is different from how it generally presents in men? How can this different presentation lead to more delays in diagnosis and inaccurate diagnosis commonly given to women such as fibromyalgia and depression? What are some solutions?

Dr. Goodman: Spondyloarthropathy was described as a form of arthritis, which is more prevalent in men, due to the differences in presentation between men and women. Women tend to have more cervical spine disease, and more peripheral arthritis, while men tend to have lumbar disease, which ascends the spine. In the 1950s-60s, fewer than 10% of patients diagnosed with Ankylosing Spondylitis, the prototypic spondyloarthropathy, were women. The male to female ratio currently is approaching one to one. Multiple factors have contributed to the solution of this problem, including the wider availability of more sensitive imaging techniques such as MRI, which can detect early changes of inflammation of the sacroiliac joints leading to early diagnosis, wider availability and decreased cost of the HLA-B27 test, as well as the increase in women in medicine.

Q3. How exactly and why are gut issues such as Crohn’s, IBS, and SpA so closely related? Also, what is your opinion on “leaky gut syndrome”/“intestinal permeability” and how or if it may perpetuate systemic inflammation or affect inflammatory/autoimmune conditions?

Dr. Goodman: The spondyloarthropathy group of diseases is characterized as an interrelated group of diseases with many...
shared features. Patients with inflammatory bowel disease such as Crohn’s or Ulcerative Colitis may have clinical features of disease shared with patients with inflammatory back pain and Ankylosing Spondylitis, such as uveitis, or inflammatory eye disease, psoriasis, or a shared family history. About 20% of patients with extra-articular disease manifestations have clinically apparent inflammatory bowel disease, and 50-60% of spondyloarthropathy patients have asymptomatic mucosal ulcerations without clinical bowel disease.

Another link to spondyloarthritis from the gut comes through reactive arthritis, which is a form of spondyloarthritis which may be precipitated by infections elsewhere, such as Shigella, Salmonella, or campylobacter, which are gut pathogens. These infections may set off an immunologic reaction leading to inflammatory disease elsewhere in the body, the joints in particular. Moreover, the bowel wall is not a complete barrier, but may be permeable to various substances, in particular in the setting of mucous membrane ulcerations are common in patients with AS or spondyloarthropathy. In this model, the molecules that are able to breach the leaky bowel wall lead to increased exposure to immunologic stimulation, which in susceptible individuals, can result in the immunologic reactions typical of reactive arthritis.

Q4. Are there anti-inflammatory foods? If so, how might they benefit those with spondyloarthritis? Are there foods that should be avoided that may cause inflammation? What is your opinion on gluten free and/or low starch diets for SpA patients? Cutting out meat or dairy? Is there anecdotal evidence from patients vs. lack of scientific validation?

Dr. Goodman: While there are foods that are known to have anti-inflammatory activity such as fish oils, these have not been shown to be of benefit in spondyloarthropathy. There are no specific foods that increase inflammation in spondyloarthropathy. In celiac disease, exposure to gluten, a specific wheat antigen, leads to an immunologic reaction in which bowel inflammation and inflammatory arthritis can occur. While this sounds similar to reactive arthritis, in fact, the genetic associations are quite different, and removing the gluten stimulus can resolve all the symptoms of celiac disease. For reactive arthritis, once the antigenic stimulus produces the disease manifestations, they do not resolve after the precipitating infection is cleared.

Q5. Are there other non-medicinal approaches to improving spondyloarthritis symptoms (i.e. exercise, alternative medicine, meditation) that may be helpful for SpA patients?

Dr. Goodman: All patients with spondyloarthritis should see a physical therapist. This is critically important as none of the medications, which are extremely helpful in treating the symptoms of spondyloarthritis, have been shown to reverse or prevent the stiffening of the spine, in those who are affected. Stretching and extension spine exercises are very important for patients to maintain optimal function.

Q6. Why do some women with SpA go into remission during pregnancy? Is it because of hormones or other reasons? Could it be something to investigate to find medicinal use for patients?

Dr. Goodman: While there are differences in the clinical features of SpA in women compared to men, no difference among women has been seen with use of oral contraceptive pills, which are a source of exogenous estrogen. The differences between men and women in clinical SpA features such as more neck and knee disease in women or more foot involvement in men, has not been clearly attributed to hormones. In regard to pregnancy, while one study described improved back pain in the first trimester of pregnancy, by the later stages, back pain had returned and worsened, although back pain returned to the pre-pregnancy level postpartum. Unlike patients with rheumatoid arthritis, who frequently report improvement in RA signs and symptoms during pregnancy, patients with AS and SpA typically report higher disease activity, possibly due to the mechanical stresses of pregnancy.

Dr. Susan Goodman is a Rheumatologist at Hospital for Special Surgery. She specializes in treatment of patients with inflammatory arthritis such as rheumatoid arthritis, psoriatic arthritis, and spondyloarthritis.
Q1. What is your opinion on ‘triggers’ for SpA (i.e. trauma, infections, etc.)?

Dr. Ashany: Spondyloarthritis is thought to occur in individuals with a genetic susceptibility for the condition who are then exposed to an environmental trigger. In many cases, the trigger is unclear. However, in a good percentage of people, there is a clear relationship to a preceding infection. The relationship between certain spondolytic conditions such as reactive arthritis to bacterial infections of the gut (Salmonella or Shigella amongst others), and to Chlamydial infection of the genitourinary tract is well established. The roles of other infectious triggers are not as clear. Although there are reports by patients that work stress or physical trauma occurred prior to the onset of spondyloarthritis, studies suggest that these factors are only a small part of the environmental triggers that lead to the development of the illness.

Q2. Can you discuss the body’s adaptation to the biologics and why, for some people, they become less effective over time? Do you have any suggestions on how to decrease the chance of this happening?

Dr. Ashany: There is recent evidence that the formation of anti-drug antibodies, particularly in response to biologics, which are monoclonal antibodies such as Infliximab and Adalimumab, is a mechanism leading some biologics to become less effective over time. Anti-drug antibodies form because a patient’s immune system begins to recognize the drug as foreign, and manufactures its own antibodies which bind to the drug and make it less effective. Some studies suggest that the use of an additional immunosuppressive medication such as Methotrexate along with a biologic may diminish the formation of such anti-drug antibodies or may improve the function of biologics through other mechanics.

Q3. What can you do when biologics and NSAIDs are not enough? Would you also address the issues that come with the use of narcotics? In addition, is there a benefit to an exercise program and physical therapy for patients with SpA?

Dr. Ashany: A recent article reviewing multiple studies on the subject concluded that in Ankylosing Spondylitis, there is evidence supporting exercise interventions in improving physical function, disease activity, and chest expansion compared to patients who don’t exercise. Although less
robust, there was also evidence that exercise improves pain, stiffness, spinal mobility and cardiorespiratory function. Supervised group exercise yielded better outcomes than unsupervised home exercise. For patients with arthritis outside of the axial skeleton, for example, at the hip, corticosteroid injections are also an option. Use of other oral and topical pain medications can be useful for some patients. Non-narcotic pain therapies such as Tramadol and SSRIs such as Cymbalta can also be employed.

(Editor’s note: As of July 2014 Tramadol has been reclassified as a narcotic. It is considered a Schedule IV controlled substance.)

Issues related to the use of narcotics for chronic musculoskeletal pain include managing side effects of narcotics and awareness of the potential to develop tolerance to these agents. Studies in spondyloarthropathies demonstrate that analgesics in these conditions are rarely effective as mono-therapy, but can be employed to treat residual pain not controlled by biologics and NSAIDs.

Q4. SpA is sometimes referred to as an autoimmune disease, and this is technically incorrect. Could you explain the difference between autoimmune and auto-inflammatory/immune-mediated?

Dr. Ashany: Spondyloarthritis (SpA) is a chronic immune-mediated inflammatory disease of unknown origin. Because spondyloarthritis does not share genetic risk factors, a presence of disease specific autoantibodies, nor a response to therapies targeting the T-cell or B-cells of the immune system which seem to be important in other autoimmune diseases such as lupus and rheumatoid arthritis, the cause of spondyloarthritis is likely to be different than those of autoimmune diseases. T and B cells belong to a component of the immune response called the adaptive immune system. There is now increasing evidence implicating immune cells from a different component of immunity, named the innate immune system, in having a role in spondyloarthritis. The cells, which are important in this system, macrophages, mast cells and neutrophils, drive inflammation in spondyloarthritis. This system can be triggered by bacterial infections as well as mechanical stress. Importantly, these cells produce cytokines such as tumor necrosis factor, interleukin 1 (IL-1), IL-23 and IL-17, which can be targeted therapeutically. The predominance of a role for these innate system cells over the lymphocytes of the adaptive immune system cells suggests an auto-inflammatory rather than an autoimmune origin of inflammation in spondyloarthritis. Therefore, targeting innate cells or their inflammatory mediators may be more effective than T-cell or B-cell-directed therapies in spondyloarthritis.

Q5. If there are signs of depression and hopelessness in patients with chronic pain and illness, what does the patient need from their doctors? What about their family and friends?

Dr. Ashany: Depression and anxiety are negative psychological states that are frequently observed in patients with chronic pain and illness, including patients dealing with musculoskeletal symptoms and fatigue, as may occur in spondyloarthritis. A study, which included 110 patients with Ankylosing Spondylitis, reported that depression and anxiety were present in 25 and 15 percent of patients respectively. Rheumatologic disorders such as spondyloarthritis produce many stressors that can influence a patient’s ability to deal with the disease. These include physical limitations on the ability to participate in activities both at home and in the workplace, financial hardship as a result of loss of income and high health care costs, altered social relationships as well as changes in physical appearance.

It has been noted that criticism from spouses is associated with poorer psychological adjustment among patients with rheumatic diseases whereas strong marital relationships tend to positively impact the effects of stress on disease activity. Interventions such as educational programs for patients and family members can help in teaching skills necessary to cope better with disease related problems. These programs can include teaching strategies such as relaxation techniques and learning to pace one’s activities during the day. A physician should direct patients with chronic pain to social services which are available through hospitals or disease-specific organizations and foundations. For some patients, participating in group support services can be helpful, while others may find that seeking a one on one intervention may be more helpful.

Q6. Are there new treatment options on the horizon for SpA?

Dr. Ashany: Tumor necrosis inhibitors increased therapeutic options for patients with spondyloarthropathies dramatically. However, not all
patients respond and there are patients who have an initial response, which is subsequently lost. Consequently, there is still a need for additional therapies. A variety of different biologics have been studied in Ankylosing Spondylitis, the prototypical spondyloarthropathy, and others are undergoing study currently. Results with Rituximab (targets B cells), Tocilizumab (targets cytokine IL-6), and Abatacept (targets T-cell costimulation) have failed to show a significant effect in Ankylosing Spondylitis. Currently, there are studies examining the potential benefit of other biologic therapies in Ankylosing Spondylitis. These include *Secukinumab (targets IL-17), Apremilast (targets phosphodiesterase 4), and Ustekinumab (targets IL-12/23). Although these studies are not yet completed, early evidence suggests that targeting of IL-17, IL-12/IL-23, and PDE4 may show more promising results than biologics targeting B and T cells in patients with spondyloarthropathies.

Dr. Dalit Ashany is an Assistant Attending Rheumatologist at Hospital for Special Surgery. She specializes in the treatment of systemic lupus erythematosus, rheumatoid arthritis and osteoarthritis.

*Editor's note: Secukinumab (AIN457) is the first medicine selectively targeting IL-17A with positive Phase III results in AS. Detailed results on these trials will be presented at an upcoming medical conference.
Who would have guessed that musculoskeletal radiologists and rheumatologists, very often, are not familiar with each others’ medical terminology when discussing Spondyloarthritis (AxSpA) diagnostic imaging? Well, the experts tell us that this is a true statement. Thus, in September 2014, SAA set out on a quest to address this issue.

Why, you may ask, would it be important that these two specialists share the same lexicon? The answer is a very straightforward one and it plays a critical role in diagnosis of this still often mysterious group of diseases. You see, we have come a long way in recent years in improving treatments for moderate to severe disease. So much so that the medical literature supports the notion that early diagnosis in AxSpA very often will lead to much better long term outcomes when appropriate treatment is started very early... very early within the first two years after onset of symptoms. That is the good news.

Hence, two years ago, SAA set out to explore the best possible mechanisms to accelerate diagnosis in early disease. The medical literature at that time reported a 6-8 year lag in diagnosis after symptom onset. The experts tell us that the worst structural and irreversible damage very often will occur in the first ten years of disease and therefore, it became obvious that accelerated diagnosis in early disease was paramount to avoid unnecessary human suffering and foster better long term outcomes.

In comes magnetic resonance imaging (MRI). Intuitively, our radiology and rheumatology colleagues believed that MRI would be the answer to early diagnosis but the road to harnessing this advanced tool was long and hard and fraught with perils such as cost and competing interests.

Today, though not completely ratified by all in the rheumatology and radiology community of experts in AxSpA there are recognized standards in MR Imaging in diagnosis of AxSpA in its many forms and iterations. This is where we get back to the original conversation — how to start a meaningful dialogue between radiologists and rheumatologists to improve patients’ outcomes.

One possible answer to that question was found in Canada. To be specific, in Alberta, where two physicians dedicated to improving outcomes in AxSpA patients had set up an advanced hi-tech training program. The program combines cross over learning modules for rheumatologists and radiologists to work together in advancing their knowledge base in differential diagnosis (sorting it out from other similar conditions) and 3D imaging in AxSpA. The program is delivered using specialized software (DICOM) to translate the MRI images into 3D images that can be manipulated to study all different aspects of the pictures taken by the MRI machine.
Fast forward to September 2014. With support from a generous SAA Family Foundation, SAA was able to bring the specialized workshop to LA for a proof of concept pilot in the US. I think that it is important to note that the program had already been on the road worldwide training musculoskeletal and diagnostic radiologists and rheumatologists with a specialized interest in AxSpA in countries including Israel, Korea, Brazil and Australia, as well as a variety of Canadian Provinces.

It was quite a big production to bring the whole team of experts from Canada to LA. The program called for 57 laptop computers loaded with hundreds of case studies in DICOM imaging in AxSpA, three technicians and six expert presenters in rheumatology and radiology. The program consisted of workshops in the morning dedicated to each set of experts and then brought the whole group together late morning and in the afternoon to work together. It was very exciting as we set the six breakout rooms and plenary room late into Friday night. The original laptops had been held up in customs in Brussels and we had had to scramble to rent new ones and then to preload them with the case studies, which presented a nightlong adventure.

When the morning light hit, we were ready to register our attendees. The day went off without a hitch, although that may not be exactly accurate as the breakout rooms in the hotel were quite spread out and caused one of our attendees to thank us for the “speed dating” opportunity as she raced by to attend the next workshop.

All in all, it was a wonderful learning experience for all according to the feedback forms. What was most interesting is that our attendees, ranging from young docs just starting out to heads of department at major teaching hospitals, told us that they had learned something of tremendous value that day. That they intended to put this new knowledge into practice immediately, to spread the word to colleagues and confidentially shared with us that their greatest fear now was that they had missed many a diagnosis in the past.
MEMBERSHIP

When you make a donation to a charity you are making an investment in that organization. Like any investor, you want your money to be used with care, and you expect positive results from your contribution. In the case of a charitable gift, your investment is in the mission of the organization, and its impact on your own long-term goals and priorities.

In short, you are making an investment in your own future and that of your loved ones.

In the charitable sector, the importance of accountability has created a focus on the effectiveness of organizations and the efficiency of their operating costs. But the task of determining acceptable levels of transparency and accountability can be a complex one. The media has contributed to this confusion through well intended exposes about poorly run charities with exorbitant overhead costs, but their explanations about monies allotted to the operating budget are often oversimplified and sensationalized, leading some people to conclude that any overhead costs at all are a sign of mismanagement. That’s simply not the case.

A simple rule of thumb is that the greater the percentage of revenue spent on program services, the better the effectiveness of the nonprofit. But non-program expenses are important as well. In nonprofit accounting the two line items that reflect non-program (overhead) expenses are Fundraising and Management & General, both of which play a crucial role in maintaining the sustainability and effectiveness of the organization.
FUNDRAISING COSTS

Lower fundraising costs = better return on your charitable investment

To put it plainly, certain overhead costs cannot be avoided if a charity is to meet its goals. Unless an organization is heavily funded by a government agency, or endowed by one or more “angel investors,” some amount of resources must be designated to raise the capital to continue to focus on advancing the mission.

SAA receives no such funding and relies on smaller gifts from individuals who believe in the work we are doing. Fundraising accounts for only 6% of our annual expense budget, as compared to 12% for the Arthritis Foundation, 15% for the National Psoriasis Foundation and 21% for the American Cancer Society. That means that more of our supporters’ funds are put to work directly advancing the work that we do. Lower fundraising costs = better return on your charitable investment.

MANAGEMENT & GENERAL

SAA’s independent auditors classified 15% of our expenses as going towards Management & General. That percentage includes a portion of staff salaries, rent, telephone bills, insurance, bookkeeping and just keeping the lights on.

But Management & General is also hard at work meeting our mission. For example, portions of many projects that might seem more appropriately allocated to programs such as Research or Education are often expensed as overhead:

- When we work with the American College of Rheumatology & SPARTAN to develop treatment guidelines, some of those expenses are considered to be Management & General.
- Similarly, a portion of the time we spend collaborating with researchers to launch the National Patient Registry for AS also falls under Management & General.
- A percentage of our efforts to educate the medical community in recognizing non radiographic axial spondylitis so that people suffering can receive the proper care and treatment is expensed as Management & General.

SO HOW MUCH SHOULD AN ORGANIZATION SPEND ON OVERHEAD?

The Better Business Bureau’s Wise Giving Alliance suggests that nonprofits apportion at least 65% of their total expenses to program activities. Another major player, CharityWatch, considers a 60% budget allocation to charitable programs satisfactory.

Charity Navigator also evaluates nonprofits based on allocation of expenses and awards the 4-star rating — its highest grade — to only the most fiscally responsible charitable organizations. This rating indicates that the Spondylitis Association is a trustworthy steward of the donations it receives, adhering to good governance and other best practices that minimize the chance of unethical activities.

“As the nonprofit sector continues to grow at an unprecedented pace, savvy donors are demanding more accountability, transparency, and quantifiable results from the charities they choose to support with their hard-earned dollars,” noted Ken Berger, Charity Navigator’s president & CEO, in a recent letter to SAA. SAA has received the top score – 100 – in Accountability and Transparency every single year since Charity Navigator began reporting on this criteria.

SAA currently spends 79% of revenue on program services, putting us well ahead of the pack.

And Charity Navigator isn’t alone. SAA has received the highest marks from the GuideStar Exchange, Great Nonprofits, Independent Charities of America and Health & Medical Research Charities of America to name a few. (SAA’s 990 tax return form and audited financial statements are always available on spondylitis.org.)

As we close out 2014, our eyes are firmly fixed on the challenges of 2015 and beyond. If we are going to continue to carry out our mission, we will continue to rely on the generosity of individuals, like you, who know that we are making smart financial decisions. Together we are making an investment in a better future.

Our Year-End Appeal will be in your mailbox soon. Please consider SAA in your holiday giving plans.
We live in a place and time where many of our activities are in front of us and below eye level. We drive and commute to a desk job, sit through meetings, work on laptops and tablets, watch TV, wash dishes, cook, eat, shuttle our kids, and then we exercise in ways that further reinforce these suboptimal postures. We sit too often and for too long. If it is true that we are what we repeatedly do, then we are slouched and we are bent forward.

Progressive movement programs are extremely beneficial for people with Ankylosing Spondylitis and related Spondyloarthropathies (SpA). Progressive movement programs are essentially any regular practice that includes movement and progress. Even maintenance programs are of benefit if you are happy with your current level of function. But “progressive movement program” sounds new, kind of technical and maybe a bit daunting. An easier way to think about it is “regular exercise”, but without all the baggage we’re carrying from years and decades of being told to “exercise” and our notions of what that means. In simplest terms - our bodies are built to move, yet we’re in a world where there is more opportunity to sit and be sedentary than ever before in human history. And even with the aches, stiffness, pains and sometimes severe flares we experience with SpA the right thing to do, most often, is to get up and move. So, instead of continuing with “progressive movement programs”, we will simply call it what it is, regular exercise.
Exercise may be considered the only true wonder drug. Exercise improves cardiac health, pulmonary function, vascular health, mood, strength, flexibility, endurance, balance, appetite control, weight loss and maintenance, and our general capacity to do physical work. It can also help us in recovery from injury, surgery, and the myriad insults a physical life inflicts. The dosage of exercise is determined by frequency, duration, load and intensity. The challenge for people with SpA is finding a regular exercise regimen at the right dosage, without excessive impact and extremes to avoid exacerbation of symptoms and flares. We are basically adjusting the dosage in the right way to get all those wonderful benefits while reducing the risk of pain and the setbacks that we’ve all encountered. Further, we are challenged to do this amidst a culture where “more is better” and extreme effort is glorified; we desire immediate gratification and our attention spans are ever shrinking.

**Goals & Benefits**

The primary goal for regular exercise should be improved function in a program that is suitable, repeatable, and mentally stimulating. The primary desired benefits are improved balance, posture, strength & flexibility. When selecting and implementing a new routine, we should be looking long term and consider consistency as being a much higher priority than intensity. Life, and our exercise habits are not sprints, they are marathons, and if we’re not engaged and don’t regularly do the movements and exercises, then they simply will not work.

Wilson McCoy’s article from the Fall 2014 issue of *Spondylitis Plus* outlines some of the benefits that he personally experienced from his regular practice of Tai Chi. And while his practice is relatively developed, there are studies showing that even a few minutes a day, several days a week of Tai Chi practice can produce significant changes in balance, posture, strength, flexibility, and breathing. And while we may hope that Tai Chi, or any regular exercise program will change our outlook on life, whether it achieves that or not, it can certainly improve our physical function and make life a good deal easier.

In *A Look At the Evidence: the benefits of tai chi*, also from the Fall 2014 issue of *Spondylitis Plus* we read:

“...each of the above papers issues its own cautionary disclaimer. Overall, each states that larger, randomized controlled trials are necessary to endorse a full recommendation of Tai Chi in treatment. Even the controlled study on ankylosing spondylitis states that, “We cannot completely discount the possibility that the placebo effect was responsible for the improvement.”

While larger studies are often called for, it is difficult to imagine a placebo improving strength and flexibility on a significant scale in people with SpA. And as so many studies have been conducted with good to great results, it stands to reason that the benefits outweigh any risks by a significant margin. Though clinical experience is anecdotal, I have found in my experience over the years as a physical therapist, distinct patterns in observing active and inactive people, which reinforce the findings of the studies cited.

Some ideas for regular exercise or progressive movement programs are Tai Chi, Yoga for beginners, Mat Pilates for beginners, and even Nintendo’s Wii Dance. You can find examples of all of these on YouTube. Just make sure to modify any difficult or painful movements so that you don’t injure yourself or irritate a body part. Aside from YouTube, many local recreation centers and YMCAs offer these classes, as well as water based exercise programs that can be a great place to start for those who need less weight bearing and loading.

So, exercise is good and beneficial for everyone if done consistently and at the right dosage. The benefits of a properly adjusted program should vastly outweigh the risks. Our daily activities are working against us in our desire for good posture, while our culture offers too much time to sit with promises of undoing the damage we cause through quick fixes. But despite this, we know that having a regular exercise routine that helps us practice and reinforce good posture, that helps us to separate trunk movements from those of our arms and legs, that forces us to get up and move and challenge our balance in ways we don’t do throughout our day is inherently and extremely valuable. It helps us stay active, improves our health and well being, and makes life more enjoyable. Good luck in finding, and sustaining a regular exercise routine that works for you.

Sturdy McKee is a physical therapist who has been living with Ankylosing Spondylitis for over 20 years. His primary forms of regular exercise are walking the hills of San Francisco and playing with his 3 children. He can be reached at sturdy@sfsspt.com or @sturdy on Twitter.
Patient Q&A: Cheryl Dickinson - My AS Journey

How did you get diagnosed?

My healing journey has taken me everywhere from A to “Z-Health”!

A Rheumatologist diagnosed me on November 19, 2009 with positive HLA B27 and Ankylosing Spondylitis. This diagnosis came after the previous 5+ years of chronic neck pain that traveled down to my knees and spread to other joints, making it difficult for me to walk without the assistance of a cane.

I gained weight and was in constant pain. I went from doctor to doctor, physical therapists, and tried dozens of medications. I also tried therapies including having knee surgery to try to alleviate the pain. It was after my knee surgery, and subsequently losing 50 pounds via the Weight Watchers Program, that I went to my Orthopedist and complained about the pain still being there. That’s when he ordered a blood test to check my sedimentation rate (inflammation marker) and it was over-the-top high.

I realized that over the years I had signs of joint pain, but it was never diagnosed or connected to Ankylosing Spondylitis. Through medication, first Humira, and then Enbrel, I was able to put out the inflammation fires and keep the symptoms regulated. I had already developed some damage in my spine, knees, and a partial fusion in my upper neck. I continued on the medication, started swimming, and was eventually able to go for short walks without the assistance of my cane. I really thought this was all that I could do: low impact movement.

My Rheumatologist has supported and encouraged me to lose the rest of my excess weight and do more core work. I seemed to be stuck not being able to do anything but swimming and walking. If I tried to do any aerobic exercise and felt pain or did not feel comfortable, I would stop. Given that I have the joint and neck fusion, my movement is limited.
From 2010-2012, I carried on thinking that this was going to be my life, taking mega doses of medications, and the result being that I’d be in much less pain than I once suffered in 2009. I was able to walk and swim without severe pain, but unable to enjoy any other exercise regime.

Could you talk a little about your doctor’s treatment plan for you and how you decided exercise had to be an integral part of your life? Where did you start? How were the first few weeks? When did you start feeling a difference?

My health care professionals are working alongside me to attain better health. I am fortunate to have Dr. Lianne Gensler, a wonderful Rheumatologist at UCSF. I’m being treated with Enbrel and an NSAID taken as needed. Of my own volition, I follow a Vegan diet. I enhance my plan by following a strict anti-inflammatory program and belong to Weight Watchers.

Dr. Gensler encouraged me to lose excess weight doing more stretching, core work, walking and swimming. I attempted to exercise and quickly became uncomfortable and in pain. For example, it was difficult for me to stand up, kneel down, sit on the floor, or put any kind of pressure on my knees.

It was my on birthday, January 3, 2013, when I turned 49, that the medication, a TNF-a Inhibitor, eventually stopped working. I emailed my Doctor saying, “Please, please, help me!”

I was paralyzed in pain and immobile. Dr. Gensler saw me right away, on my birthday, and put out the fire within. She regulated my medication onto a new biologic. This was a breaking point for me! I knew I needed to do something even more. Just a few months later, on May 28, 2013, I learned that spinning (indoor cycling) is a wonderful low impact workout.

On June 6, 2013, I went to Wheel House, a fitness center near my office at lunch and tried a Spin class. It was a real challenge for me, but I liked it and kept going. My determination was born. During 2013, I worked up from being exhausted after 5 minutes on the bike, to taking 30-minute classes. I never gave up and attended Spin classes once or twice a week. On January 30, 2014, I took a Spin class with a new Wheel House instructor, Nan Luma, who inspired me so much, that in March 2014, I began working with her on a personal training level, as she is an Exercise Therapy Coach at J Bodyworks in San Francisco. The foundation of the J Bodyworks curriculum is Z-Health.

Z-Health is a movement training program that focuses on the nervous system utilizing simple drills that help unclog the road maps from your movements to your brain. By doing simple Z-Health drills, you can remove blockages in the body and reduce pain! After starting Z-health training, I learned physical drills that I could use in my everyday life. I learned how to move without pain! It has changed my game, and my life 100%! I am now able to accomplish a 90-minute spin class, and I take 4-6 classes per week.
“During 2013, I worked up from being exhausted after 5 minutes on the bike, to taking 30-minute classes.”

Core work is important for seeing results. I do core workouts twice per week. The results are numerous, but the biggest difference is reducing the pain. Another benefit is making noticeable progress in my weight loss, mobility, and improved quality of life.

Your physical transformation is inspirational. Did you have road blocks along the way? What helped you get past them?

Staying present, not giving up hope, and holding on to my faith has brought me so far and I know it will yield endless possibilities. Just recently, I stopped my medications for a minor outpatient surgery. With my Doctor’s support after my surgery, I chose not to go back onto the medications right away to see if the recent alleviation of my pain through Z-Health exercises made enough of a difference so that I could stop them altogether.

I lasted only one month before I had some big medical flare ups of pain and swelling. Interestingly enough, I was able to work through the pain much quicker having had access the Z-health training system, plus doing my at home drills. I am now regulated back on the medication.

The rebound time was even quicker than when I was treated with medications in the past. I learned that movement actually decreases my pain and gets my joints moving better! Before I started indoor cycling and training with Nan, a flare-up would have sent me straight into my Doctor crying for help!

How are you feeling now? Do you still have bad days from time to time? (If so) How do you manage those?

Today, I am feeling fantastic! Sure, I have my ups and downs, but now I have some real practical go-to methods to move forward and get out of pain and into movement. When I have any joint or muscle pain, I can do some Z-Health drills and move forward in most cases immediately.

I also am much more active, which keeps my mind positive and my body moving. I think the biggest shift for me, after learning to move without pain, was that I found that there were so many more possibilities for me than settling for having a disease and being satisfied with limitations.

What does your Rheumatologist think about your progress?

My Rheumatologist is thrilled, inspired, and extremely supportive of my progress and goals. The increases in my range of motion within my neck and general mobility have really impressed my doctor! In fact, at my last appointment my Doctor said, “see you in six months”, rather than the usual three. She and I are eager to measure the progress at my next appointment!

What’s next for you?

The possibilities are endless on what is next for me now! Just recently, I purchased an outdoor bike after not riding for 27 years! Plus, I bought a Hula Hoop. I am currently re-learning riding a bike outdoors and hula hooping. My transformation has inspired me to one day teach indoor cycling and I am working hard to achieve this goal.

My desire is to take the next Spin Instructor training class offered at San Francisco’s Wheel House, the studio where I do most of my cycling. I will let go of 100 pounds, become mobile, and be a Spin Instructor — despite having AS. I will inspire anyone suffering with Ankylosing Spondylitis letting them know that there is hope for them. I invite you to Spin with me and feel successful too! Never give up!
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