ON POINT

Dear Readers,

Recently on a long drive in LA traffic following a business meeting, I had the time to think about SAA’s upcoming new Fiscal Year and the ever expanding strategic vision of our organization. Five years ago, after careful consideration and much discussion with colleagues and constituents, we determined that the landscape at that time provided clear guidelines as to just what the unmet needs were in spondyloarthitis. As such, we focused our efforts and resource allocations toward three specific areas—serving the diagnosed, serving the undiagnosed and supporting research.

The sometimes unreliable state of patient care, the difficulty many experienced when trying to access effective and affordable medications and treatments, and the need for a supportive community where those affected could learn the skills necessary to take charge of their disease drove our commitment to serving those already diagnosed.

The lack of familiarity in the medical community with spondyloarthritis and the associated unacceptable delays in diagnosis highlighted the need for us to educate physicians – from first responders to primary care doctors to chiropractors to rheumatologists – in order to better serve the undiagnosed so that they can begin treating their disease before preventable damage can be done.

And, the critical need for innovative and cutting edge medical and scientific research for this under-served and under-funded group of diseases provided the third prong in our mission-driven strategic plan – advancing research into both the causes and the cure. By directly funding novel pilot studies that have the potential to secure much larger government and industry grants once established, recruiting patients for a wide range of medical research projects and directly sponsoring up and coming researchers who show an interest in dedicating their studies to spondyloarthritis, SAA is actively working toward the day when spondyloarthitis is understood and preventable.

Over these past five years, SAA’s efforts in these areas have led to patients who are more empowered to take an active role in managing their disease and who know they have a community of others to support them; increased knowledge among patients and physicians alike which is the first step in earlier diagnosis; and many scientific breakthroughs that have the potential for more effective medications, a better understanding of the causes and the promise of a cure.

Maintaining these achievements and meeting the goals we’ve set for the future requires a focused effort in service of our strategic plan. Today, SAA’s strategic goals have not changed but they have expanded in scope as we continue to respond to the changing landscape of spondyloarthitis in the US. There is still much to be done. And with the generous support of our members, supporters and friends like you, I have no doubt Fiscal Year 2016 will be every bit as successful as the past year has been.

Laurie M. Savage
Executive Director
On March 21st 2015, SAA hosted a free Spondylitis Educational Seminar in Los Angeles, CA. The program was broadcast live online, as well as recorded and made available for later viewing. We received countless notes of thanks and praise from people watching the broadcast. Below are a few we wanted to share. If you have yet to watch the recording of this program, you can do so on SAA’s website, at http://www.spondylitis.org/press/news/630-la-seminar-video.aspx

We share a few pictures and briefly recap the event on page 8.

“I wanted to thank you all so much for everything you do, have done, and will continue to do for all of us. It is very doubtful that you will ever truly understand the amount of gratitude and appreciation we have for all of your hard work, dedication and sacrifice. I was all booked and ready to attend [the spondylitis educational seminar in Los Angeles] but due to my health at this time I was unable to make it, so this is such a blessing and gift for me personally. I think what I am and will enjoy the most is the “Testing One Two; Testing One Two!” Can you tell I am excited? I am sitting here in bed all ready to attend! Good luck to you all, Kick Some AS!”

~Cookie Hopper
Texas

“I have learned more from this seminar than I have the last 16 months with my Rheumatologist! Thank you so much from Central PA.”

~Jennifer Yoder
Pennsylvania

“Thanks for this opportunity. I learned a lot. It really got my husband (he watched with me) and I excited about watching more podcasts and getting involved with SAA. Thank you!”

~ Sid-Ali Hamouche

“Namaste SAA Staff...I am sending an additional $100 this evening after watching the archived live streaming of the recent seminar. The three speakers were excellent, and I picked up some good tips on managing my AS. I hope that you will continue this method of communication along with all the other services you are currently providing members. Keep up your good work, and know that you are making a positive difference in the lives of many grateful people.”

~ Russ McDonald
California

Editor’s Note:
Thank you everyone for your kind words and touching comments! We plan to continue live streaming our patient educational programs where possible.
What is the most disgusting substance you can imagine? Most of us would say that human feces has to rank right at the top of any list. But life is filled with ironies. Human feces is emerging as a potential treatment for ankylosing spondylitis. Let me explain why.

Ankylosing spondylitis is a disease in which our immune system plays a critical role. Our immune system has many components and many checks and balances. The heart and soul of the immune system is the white blood cell or leukocyte. One type of white cell, the lymphocyte, plays a very prominent role in immune-mediated diseases like ankylosing spondylitis. We know that the immune system is vital in this disease because of studies on pathology in joint tissue, because of studies with laboratory animals, and perhaps most of all, because therapies that are beneficial for ankylosing spondylitis work by affecting some aspect of the immune response.

Our immune system evolved to protect us from the danger that lurks with invading micro-organisms such as bacteria or viruses. The immune system is so vital to life that even plants and bacteria have evolved clever ways to defend themselves with an immune response.

But the immune system must be selective in its approach. If the immune system attacked all bacteria, the body would be destroyed. For example, bacteria live on your skin, in your mouth, and throughout your digestive system. In fact, you have ten bacteria living in your intestines for every mammalian cell in your body. From this perspective, ninety percent of every living being is bacteria! If our immune system deployed its weapons to destroy the bacteria that happily co-exist with us, wide-spread inflammation would result wherever bacteria are present. In fact, this is the currently accepted theory as to what causes Crohn’s disease and ulcerative colitis, the two most common forms of inflammatory bowel disease. Our immune system attacks some of the bacteria in our intestines, resulting in diarrhea and abdominal pain.

Bacteria need to find a public relations firm to represent them. Most of us hear “bacteria” and we think of infections and the harm, even death that can result from many different bacterial infections. But bacteria are also essential for life. For example, much of the vitamin K produced within our body is made directly by bacteria. One of the most essential roles for bacteria is to educate the immune system. Mice can be raised “germ free” so that no bacteria ever live within the gut. In these germ free mice, an effective immune system never develops. While it’s absolutely true that bacteria can do harm, it’s also true that bacteria are essential for life.

So how does this relate to ankylosing spondylitis? Well, first of all, ankylosing spondylitis and inflammatory bowel disease have a lot in common. In ankylosing spondylitis, the majority of sufferers have microscopic amounts of bowel inflammation that can be detected by colonoscopy. And conversely, in inflammatory bowel disease, some patients develop arthritis in the spine and elsewhere as is characteristic of ankylosing spondylitis. Inflammation inside the eye or uveitis also occurs in both inflammatory bowel disease and ankylosing spondylitis.
Last year, my colleagues and I reported on the gut bacteria in rats that have the human HLA B27 gene, the gene that readers of Spondylitis Plus will recognize as the one that most affects the likelihood to develop ankylosing spondylitis. Our observations appeared in the journal, PLoS One. (PLoS stands for the Public Library of Science. The journal is available for free on the internet.) We found that the bacteria in the rat intestine were altered just by being HLA B27 positive. In March, 2015 scientists from Australia and Italy reported in the journal, Arthritis and Rheumatology, that bacteria in the intestine are also altered in patients with ankylosing spondylitis.

Of course, it’s possible that these changes in bacteria have nothing to do with what is causing ankylosing spondylitis. Except that there are models in rats and in mice in which an illness that resembles ankylosing spondylitis can be induced. And in both the rats and the mice, elimination of the bacteria pretty much eliminates the joint and bowel disease.

The crudest way to change your gut bacteria would be through a technique now known as FMT, fecal microbiota transplant. While the idea of ingesting someone else’s bowel movement sounds absolutely disgusting, in 2013 a study in the New England Journal of Medicine showed that FMT could be life saving for a bacterial infection known as C diff colitis. One does not actually ingest poop. Instead the bacteria from the bowel movement are isolated and then swallowed as a capsule or passed directly into the stomach through a tube, or given rectally as an enema. This same approach has been used to treat inflammatory bowel disease, and while it is not universally effective, the results are encouraging.

A more elegant and more appealing approach to fecal transplant would be replacing or changing just a single type of bacteria, as is attempted with a probiotic. The complexity of the bacterial ecosystem in the gut with nearly 100 trillion inhabitants makes it difficult to find a single or limited number of culprits that cause ankylosing spondylitis, but this is a possibility. The progress in this area of research is very encouraging.

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Gut bacteria are also very much affected by diet since what we ingest provides the substrate for bacteria to live. Diet is as complicated as the bacterial ecosystem in the gut. We are still learning which foods might have an anti-inflammatory effect. Antibiotics also change the gut microbiota, but this effect is temporary because bacteria quickly develop resistance.

Bacteria produce a number of chemical products that affect the health of our intestines. One of these chemicals, for example, is propionic acid. A change in the microbiome would result in changes in the chemical balance within the gut. Possibly this chemical balance could be restored without actually changing the bacteria. One strategy might be to simply drink propionic acid. A number of laboratories have recently reported exciting data in laboratory animals suggesting that propionic acid or other so called short chain fatty acids could be used to improve the health of the bowel. And while we do not know this for sure, I think that it is very likely that a healthier bowel would be an effective treatment for ankylosing spondylitis. The benefit from sulfasalazine for some patients may come from this basis.

The microbiome is a term that is used to describe all the micro-organisms and their products associated with the human body. Intense study of the microbiome has been undertaken for less than a decade. The coming decade should help us discover more specific microbial changes associated with ankylosing spondylitis. We will also gain more knowledge about how diet affects the microbiome and we will develop ways to restore the health of the bowel, sometimes by replacing or eliminating specific bacteria and sometimes by replacing or eliminating the products that bacteria make or induce within the intestine. In the meantime, FMT, the transplantation of bacteria from feces, is being actively studied to treat inflammatory bowel disease. My colleagues and I hope that by 2016, we will be allowed by the FDA and ethics committees to try the same strategy in a limited number of patients with ankylosing spondylitis.

I have been studying ankylosing spondylitis for 37 years. Until recently, no one could have convinced me that feces might just be the key to understanding this disease.
Why don’t we exercise? We all know that it is important. We have also heard the myriad ways it can benefit our health. Exercise can help with blood pressure, cholesterol, blood sugar levels, flexibility, cardiac health, improved mood, better sleep, and more. Indeed as a physical therapist we tend to be evangelists around this. So why don’t we do more of it?

Lack of time is the thing most frequently cited, at least in my very non-scientific survey of people I know, and from 15 years of patient care. But time is the one thing that we all have the same amount of. So why is it, or rather how is it that some people find the time to do more exercise? Is it better time management? Establishing different priorities? Or could it be that some have figured out ways to make physical activity less impactful on their time?

Aside from time, many of us have some misconceptions around exercise and physical activity that can and should be overcome. We may believe that exercise by definition is rigorous. We may fear the inconvenience of preparing, buying equipment, clothes changes, as well as the cleanup afterward. We, most of us, would like to avoid driving to the gym, or even going at all. And the good news is we don’t generally have to. And exercise does not always have to be so rigorous that we must shower afterward, or even change into specific clothes. If we reframe our ideas of positive physical activity, we are more likely to integrate it into our lives than if we see it as yet another project to be taken on.

When I speak for the Spondylitis Association of America, people hear me say that you do not wait until Saturday to brush your teeth for 45 minutes. It simply would not work very well, and we know this. Yet, this is often how we treat physical activity. If we would treat exercise more like we do dental hygiene, by doing a little each day, then we would accomplish far more over time than if we set aside a large chunk of time once a week.
Activity is something we can often mix into our day. It is important to find daily opportunities to do this, and to take advantage of the moments when we can take part in some type of physical movement. Is there an opportunity to walk your children to school? Can you get a dog that will force you to get up and move, and walk a few times each day? Are there a set of stairs that are convenient, that you could practice walking up and down 3, 5 or 10 times each day? And there are tricks that we can all do to introduce more physical activity into our day. For instance, we can add a few squats into our routine when we get up and down from the couch simply by repeating the motion before moving on; balancing on one leg at the kitchen counter for a few seconds before doing the dishes, or while in line at the grocery store, is another of my favorite stealth exercises; doing a single stretch after getting out of the shower is a great way to improve or maintain flexibility without a huge time investment. Be creative and think about simple hacks to allow a little bit more movement during each day. It will burn calories, help with your strength, improve your conditioning, and help you sleep better.

Ideas for activity inclusion in your daily routine:

- Take walking meetings.
- Stand while on the phone.
- Dictate the first draft of articles & longer emails while standing up or walking.
- Do heel raises while waiting in line or on hold.
- Balance on one leg at the kitchen counter.
- Choose three different stretches & rotate one each day after getting out of the shower.
- Stand up and reach to the sky, do squats, or a favorite simplified yoga pose during commercials.
- Park farther away from your office, store entrances, school, etc.
- Use a bicycle for errands where safe and feasible.
- Schedule some kind of enjoyable, physical activity with a friend to augment the rest.
- Set calendar reminders to try some of these things.

Another way to incorporate more activity is to find the thing you’re passionate about. To this day if you place a ball at my feet I have to start moving around and kicking it. I will start jogging and kicking and passing and dribbling out of sheer joy (or compulsion). I’m a little bit like a dog with a ball. So, if I can find situations to do that it will make me work on strength, balance, and movement. Is there something that automatically gets you going? Is there an opportunity to join a league, or a team that has a regular schedule? It really doesn’t matter the sport, just that it’s something you enjoy and will stick with. And think outside the box. Your sport and new passion might be bocce or lawn bowling, fencing or kendo, Tai Chi or yoga; it might be swimming, or water aerobics, or even sailing. There are all kinds of groups doing sporting activities if you just look for them. It need not be the sports we see on TV.

The difficulty with all of this isn’t the not knowing. We read articles. We watch videos. We hear from our healthcare providers. We know that physical activity is good for us, and important to do regularly. It will help us maintain our independence as we age. It will make other activities more enjoyable and easier to tolerate. It will help us keep up with our children and grandchildren, or our younger friends. The difficulty with all of this is that it is a form of behavioral change. So, our challenge is to trick ourselves into making physical activity more of a habit, and less of a chore. Mixing it into our daily routine is one way to start this. And being willing to share your new habit with your family and friends is another. Some may resist, but you will likely find that the majority are very encouraging.

“The journey of a thousand miles begins with one step.” (Lao Tzu) Begin your journey today by taking that one step. Try it now. If you can - do a couple of sit to stand squats, or some heel raises, or balance on one foot right now; put this magazine down and try it. You might find that it makes you happy. And if you’re happy you’re more likely to do it again later today and tomorrow. And what simpler way to bring yourself a little bit of joy each day?

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 three children. He can be reached at Sturdy@sfsspt.com or @Sturdy on Twitter.
April at SAA means Spondylitis Awareness Month and the creation of an awareness campaign.

This April we launched #SpondyAwareness2015, a Social Media Campaign in the form of a contest.

The premise was simple: Use Twitter or Instagram to share your spondylitis awareness posts. Make them educational, and sharable, and you could win our top prize – An iPad mini! We asked, and our social media community answered.

We’re sharing some of the wonderful awareness posts generated by this campaign. We hope you enjoy them.

Congratulations to @sraslim, whose post, “Played Hopscotch,” was selected our winner!

Our thanks to everyone who participated in our awareness campaign, sharing countless spondylitis educational and awareness posts with their online communities.
Comedy or Tragedy?
One Heroine’s Spiritual Journey to Write Her Own Story

By: Helen Scharber

How to tell my story of AS… Is it a tragedy - a story of pain, loneliness and despair? Or is it a comedy, featuring ridiculously incompetent medical professionals? Is it a heroine’s tale, full of challenges and obstacles to overcome? Or is it perhaps a spiritual journey, in which I realize the greater purpose of all this suffering. I’m 34 now, and over the 12 years that I’ve had AS symptoms, I’ve told myself all these stories. On bad days, there is a lot of self-pity.

Why, I’ve often wondered on those days, do other people my age get to work all day and go out dancing at night, while I can barely keep up with my job, much less a social life? Why did my doctors insist for so many years that there was nothing wrong with me, sending me on an expensive, disappointing, and sometimes shame-inducing search for answers? And why, most of all, isn’t our economy and society set up in a way that sees all the good I have to contribute while also cutting me some slack when I’m down?

But on good days I am grateful for the ways AS has helped me become a better person. All this pain and fatigue, the middle-of-the-night wakeups, the frustrating conversations with well-meaning people - all of these things have helped me develop patience. I’m more compassionate now. Living with an invisible illness reminds me that everyone has challenges in their lives, big and small, visible and hidden. I’ve learned to ask for help (sometimes) because I can now see that the idea of independence is largely an illusion - we’re social creatures and we need each other to live. I’ve also begun meditating and discovered the freedom in paying more attention to what is happening right now.

I finally figured out that I had AS two years ago through an internet search, and my self-diagnosis was confirmed by a rheumatologist. Having a name for this disease has been helpful - doctors take me seriously now, my workplace has made some accommodations, and I understand better the connections between the pain, fatigue, and gastrointestinal symptoms I’ve had for years. Not wanting to start biologics right away, I tried several alternative approaches, finding nutritional therapy and dietary changes very beneficial. My symptoms aren’t gone, but they tend to come and go more quickly now, and my life - while perhaps not normal for a young, single woman - is a lot less dominated by AS.

Over the last couple of years, the stories of people living with AS have given me a great deal of comfort, advice, and hope. For my part, I’m finally figuring out that AS - like life - is terrible, beautiful, exciting, boring, scary, and hopeful. I’m writing my own story.
It’s not uncommon for patients with rheumatic disease to have mental and emotional reactions to their diagnosis and ongoing treatment. These psychological reactions can affect the patient physically in terms of disease progress, pain and overall quality of life. There are additional mental implications for the patient with regard to working with the rheumatologist to actively participate in decision making about their treatment and care.

In addition to dealing with chronic pain, which can cause significant frustration, patients with rheumatic disease frequently struggle with depression and anxiety. In one study of 11,704 patients with rheumatic disease, researchers identified depression in 15% of patients with rheumatoid arthritis (RA) or noninflammatory rheumatic disorders and in 34–39% of patients with systemic lupus erythematosus (SLE) and fibromyalgia. By comparison, 6.9% of the general U.S. population suffers from depression, according to the National Institute of Mental Health. In patients with RA, depression and anxiety have been correlated with multiple measures of disease-related pain and functional impairment, as well as social difficulties.

Another study of 4,994 participants, including 3,635 patients with skin diseases (e.g., psoriasis) and 1,359 controls, identified clinical depression in 10.1% of patients vs. 4.3% of controls, clinical anxiety among 17.2% of patients vs. 11.1% of controls, and suicidal ideation among 12.7% of patients vs. 8.3% of controls. Psoriasis also has been linked with feelings of stigmatization, and researchers report that compared to patients with psoriasis, quality of life is further decreased in patients with psoriatic arthritis.
In the rheumatologist’s office, it’s important to recognize emotional and mental responses to chronic disease. The rheumatologist can refer the patient for help and implement a multidisciplinary approach to help the patient cope. In learning to cope, the patient can see improvements in disease progression and quality of life, as well as accept responsibility for treatment and participate in decision making.

**Strategies for Helping Patients Cope**

As research into the mental and emotional effects of rheumatic disease expands, the need for psychological interventions in addition to rheumatologic interventions becomes increasingly apparent. For example, researchers who identified a significant link between disease-coping strategies, itch, and quality of life among 60 patients with psoriasis—particularly women and older patients—concluded that psychological interventions are warranted in this population.8

“Targeted interventions to identify and address depression and anxiety can have an important impact on outcomes,” says Theodore Fields, MD, FACP, director, Rheumatology Faculty Practice Plan and professor of Clinical Medicine, at Hospital for Special Surgery (HSS), Weill College of Medicine of Cornell University, New York. “To get better, patients with rheumatic disease need to get into an effective exercise program find ways to keep functioning at the highest possible level and, when indicated, closely adhere to a medication program. When patients are overwhelmed, it is very hard for them to focus on these issues.”

One strategy for rheumatologists is to use the time during office visits to uncover the specific reasons for a patient’s anxiety or depression and to encourage them to talk about what’s on their mind.

It’s particularly important to help patients deal with psychological responses to rheumatic disease early on, and it helps to ensure the patient’s spouse or a family member is present during early meetings, according to Michael Weisman, MD, chair of the Division of Rheumatology at Cedars-Sinai Medical Center, Los Angeles. After the initial diagnosis is “a time when the conversation really needs to be completely open,” he says. Dr. Weisman uses humor and storytelling to try to put patients at ease and encourage them to be open about their concerns and to ask questions about their future and potential treatments. Keeping the conversation going during subsequent visits helps bolster patients’ confidence to talk about what’s bothering them, Dr. Weisman adds.

Another strategy is to encourage patients to attend support groups. Support groups have been shown to positively affect the lives of patients recently diagnosed with RA, according to an HSS study.9

**Shared Decision Making**

It has long been recognized that patients better comply with treatment when they have the right education.11 Talking through the options and providing sufficient information are important so patients can participate in making decisions about their care and overcome their fears about medications. With regard to starting therapy with disease-modifying antirheumatic drugs (DMARDs) specifically, researchers in The Netherlands noted that patients may perceive that the therapy is aggressive or harmful, or they may worry about side effects, influence on fertility or pregnancy, the length of time the medication takes to be effective, how it is administered and issues associated with long-term treatment.12

“Few patients are active participants by nature; most patients are not even aware of having a choice,” says Ingrid Nota, PhD student, University of Twente, Department of Psychology, Health and Technology, Enschede, The Netherlands. “Stating the decision to be made and which role the patient can have in the decision-making process (i.e., acknowledging the relevance of patient participation and supporting patients to increase their confidence/self-efficacy to fulfill that role) is the first, and maybe most important, step to take.”

“For rheumatologists, it is important to realize that not all patients want or are able to make the final choice for medication, but do have an opinion and preference on certain aspects of the medication,” Nota says. Critically, rheumatologists should ask the patient, “What matters to you when taking medication?” Nota explains.

Another study by Nota et al involved sending questionnaires to 894 patients with RA, psoriatic arthritis or ankylosing spondylitis, in which the majority of respondents (response rate 58%) voiced a preference for shared decision making.13 Further, patients who felt involved in the choices about their treatment tended to be more satisfied with their care—even if they felt that they were involved in too many choices. Conversely, patients who were left feeling that they wanted to participate more were less satisfied with their care.
In the end, it comes down to the fact that knowledge is empowering. The more the patient knows and understands, the more promising the outcomes. A recent study showed that higher baseline mindfulness (i.e., conscious understanding) among 201 patients with RA was significantly associated with less disability-related psychological distress at one year of follow-up.14

Another key is to help patients understand their own emotional and mental reactions to their disease, including reasons that they don’t follow the prescribed regimen. “Maybe for some it’s financial,” Dr. Fields says, “but for many it’s psychological—fear of side effects, denial, or general stress is preventing them from doing something that has a very high benefit-to-risk ratio and can help them a lot, but they’re not doing it for psychological reasons.”

Batterman adds that “addressing the psychological and psychosocial needs of the patient contributes to adherence [and] is a very important concept. That helps in the management of the disease itself, but it really contributes to quality of life by providing disease management and coping skills. And that’s really our ultimate goal.”

References
In the past two and half years as a support group leader, I’ve met over a hundred people living with spondylitis. We’ve sat face to face and shared experiences, asked each other questions and shared tips on exercise, medications, relationships, work, school, etc. Some people were just diagnosed, some lived with spondylitis for several decades. Some people live nearby, some take a bus or car for hours, some travel from other states; one person joins us when he is in town from Europe. Only once had someone said that they had previously met another person with spondylitis prior to coming to an SAA support group meeting.

SAA is the only spondylitis organization that, for 30 years, continually creates these opportunities to sit across from someone else who truly understands. This is just a part of the valuable work SAA does, which is broad in scope. Whether it’s research, support, education or advocacy - our bottom line is benefitting people living with spondylitis. SAA is continuously at the forefront of every major development in the quest for the cure and support of spondylitis. We support research for people with spondylitis and only for spondylitis. Spondylitis is a unique disease that requires undivided attention. Gifts to the Spondylitis Association of America are used for spondylitis. If we don’t concentrate on spondylitis, who will?

This past week I received a planned gift from someone I’ve never spoken with. He wouldn’t be considered a rich man, but what he accumulated over his lifetime was donated to the Spondylitis Association of America. The gift was in honor of his nephew. He did not ask for recognition for his gift. Spondylitis affects not just those living in pain. It affects loved ones. A planned gift is a value statement, an unconditional love statement. For me it’s a way of saying “I’ve lived my life with spondylitis and I want the work - to find a cure and to help others - to continue.” His gift is being put to excellent use. Because of the generosity of our donors, SAA is shortening the time it takes to make a diagnosis, supporting research, providing education to doctors and other medical professionals and providing accurate information to people living with the disease so they can make informed disease management choices.

Please let me know if you have decided to include the Spondylitis Association of America among your beneficiaries. I also welcome calls to share experiences living with spondylitis, one-on-one. (818) 892-1616 or legacy@spondylitis.org.

Please visit www.spondylitis.org/quest for more information.
There’s been some consensus that there will be gaps to fill in healthcare services due to the aging baby boomer population, as well as the growing rates of chronic health conditions. Most people cite the obesity epidemic, heart disease, cancer, and diabetes as chronic conditions but unfortunately the rheumatic diseases get little to no press time. This article will serve to answer two questions. First: With more people and fewer healthcare workers, how can I get the most out of my trip to the doctor’s office? Second: How can the nurse help me in this quest?

The following are 10 tips for productive and informative office visits. Table one (on page 17) will recap these tips for you as a handy guide.

Prepare Yourself
Try to avoid waiting room purgatory or at least be prepared for it to help decrease your stress. The whole waiting room experience can be frustrating. Waiting is stressful on our well-being. We can try to change or at least adapt the situation. Find out ahead of time from the office receptionist some specifics surrounding your visit. Does the doctor start on time? Do they tend to run behind schedule - if so, how far behind? The office staff knows the doctor’s behavior and you should as well so you can prepare for your visit and bring something to occupy your mind. After all, they will appreciate having one less angry patient in the waiting area. Ask questions like, “Does each patient have a specific appointment time or are they in blocks of time?” For example, four patients in every 15 minute block is a clear sign of poor planning and will often result in delays. Additionally, try to snag the first appointment of the day and avoid Mondays and Fridays. When you sign in to the reception desk ask if the doctor is running on time and if not, how far behind the schedule is. Your time is valuable and your comfort is necessary to prevent flares of your disease.

Prepare a List
Come prepared with a list of questions you need answers to as an outcome of the visit. Prioritize your list. In a perfect world, the doctor would be able to answer all of your questions and concerns, but in reality, time may not allow it. Have the top three questions you need addressed at the top of your list. It is...
perfectly good practice to show the list to the doctor. In fact, show the list to the person taking you to the exam room, and ask them to make a copy and show it to the doctor. This gives the doctor some extra time to think about the best course of action for your needs. There have been numerous studies in several different disease populations that show doctors interrupt their patients after an average of 20 – 30 seconds of talk. Sometimes the environment, the “white coat”, or just the unknown affects our thinking. It might help to rehearse your main concerns at home so you may speak up confidently and get to the main points.

Prepare a Summary
Technology is literally at our fingertips. We are bombarded with information. Wading through medical information on the web is daunting and the content on a particular subject matter is often oppositional. Conducting your own search for answers and researching your disease is admirable. However, it isn’t advisable to come to your appointment armed with a stack of printouts, or an iPad full of bookmarked sites for the doctor to read. The time allocated to your visit is finite, and though they may be interested in what you’ve found, they will not be able to read it all. Your best practice is to be prepared by condensing your material; bring one or two articles you’d like an opinion on, or wish to have interpreted. Always know the original source, the authors, and summarize in a few sentences what you need from the doctor regarding the finding. Having a copy for the doctor to briefly review if they choose is also a good idea. For example, you found an article on-line from the Cleveland Clinic about the use of TNF alpha blockers in spondyloarthritis and you would like to know if it could apply to you. If possible, you could have a copy of the one article to give to the doctor. Information in the form of multiple articles and resources can be overwhelming, and you want your doctor to focus in the time you have during your appointment.

Buddy-Up
Bring someone with you, especially if you are prone to forget or have a well-meaning loved one who wants to know every detail of your visit. As said before, the whole visit to the doctor can be stressful and we do forget things, or may receive too much information to process at one time. Take an extra pair of trusted eyes and ears to keep you on track and capture information you may miss.

"Take an extra pair of trusted eyes and ears to keep you on track and capture information you may miss."

Bring a List
Bringing a list, or better yet, the actual medications and supplemental products with you is an all-around best practice for you to follow. Do not assume your primary care doctor informed your rheumatologist you had a severe infection recently and you were treated with high level antibiotics which you just completed. Keep your own medication record that includes current medications and all supplements, over-the-counter medications, and anything you started and stopped in the months in between your visits with the rheumatologist. Let the doctor and staff have the best possible picture of your health.

Share
Sharing your medication and supplement history with your healthcare team is an important aspect of ensuring you receive the best care and treatment. Another important aspect is preparing and sharing a health diary. Personal information like eating habits, stressful events, and reactions to certain situations, climates, or foods can be of tremendous value in your diagnosis, treatment and care. How you are coping and reacting to your environment, medications, and activities in your daily life are critical pieces of information your doctor needs to help you better manage a chronic disease.

Ask
This tip is of utmost importance. Don’t be afraid to speak up. This is your time at the doctor’s office. Repeat after the doctor in your own words to see if you understand and get confirmation. Ask every time you do not understand something. If you need more time and do not fully understand something being said to you, ask for more time to talk about it. If the doctor is not available, ask if there is a nurse or physician assistant (PA) available to help you. If a nurse or PA is not available, you may need to schedule an appointment just to have time to talk to the doctor about your concerns.

Receive
Ask for and receive written or recorded information as resources to take home with you. Brochures and other educational materials provided by your healthcare team will give you a good source of accurate information. Your notes from your visit are a valuable resource; have your doctor, the nurse, or PA review what you have written for accuracy before you leave.

Reconnect
It is important to know what your doctor prefers as far as communication with you is concerned. How do you reconnect after the appointment? We all have questions and may need clarification. Simply ask by saying, “I know I’ll have questions, who should I call and what is the process?” Can you reconnect with the office by email? What is the best form of communication? If the phone is the preferred form of communication, who takes the message? When are calls returned? It is perfectly justifiable to be an active and informed partner in your personal care. Sometimes you may need to speak up, ask questions, and follow up.

www.stopas.org
As you have read thus far, there are several ways to prepare for and receive the maximum benefit from a visit to the doctor’s office. As a nurse, I believe the best tip is saved for last, and it is this: network with your nurse advocate. One of the best ways to get the most out of your visit to the doctor is to identify and network with your nurse. Now, herein lies the misconceptions of who your nurse advocate is, and what they can do for you. Let us begin with establishing the “nurse,” who they are and who they are not.

Network

Nurses are healthcare professionals. We practice the fine art and science of nursing. We possess skills and competencies acquired through years of education, experience, and innovative practice. The American Nurses Association Social Policy Statement (ANA, 2010, p.13) defines nursing as “the protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, communities, and populations.”

There is a disconnect between the public’s perception of nurses, and nurses’ perception of nursing. Nurses can at times be poor communicators of our worth in the healthcare community. Many are content to work diligently behind the scenes, making the impossible happen, but not speaking up and taking any credit. Truth is we do work behind the scenes. We are critically thinking, questioning, and analyzing treatments; we are also solving problems, protecting, and serving as patient advocates.

"If you need more time and do not fully understand something being said to you, ask for more time to talk about it."

The last item in this list, “Network”, starts with getting to know your healthcare team, specifically the nurse on your doctor’s team. Table 2 shares a bird’s eye view of the many different levels and educational backgrounds of nurses. The entry level into practice as a nurse is the Licensed Practical (or Vocational in Texas and California) Nurse. This level requires specialized training from Registered Nurses in a classroom setting, as well as various clinical settings. Once a program is completed and a degree conferred, the potential candidate may take a national examination, which they would need to pass with a certain score in order to be licensed to practice in their respective states. Interestingly, it is only the state legislators who have the power to change law regulating the practice of nursing in each state; no other governing body or entity has such power. This applies to Registered Nurses as well. There are many levels and several educational paths for the Registered Nurse as Table 2 indicates. There are levels all the way through to post-doctoral levels. At any basic entry level, in order to be considered a Registered Nurse, the potential candidate must have successfully graduated from an accredited nursing program and successfully pass a national examination in order to be licensed to practice in their respective state. In order to retain the license, states require differing hours of continuing education credits per year. Thus, nurses become lifelong learners. There are many levels of master and doctoral level specialty and sub-specialty practice, many of which have certifications to acknowledge the attainment of advanced knowledge and practice for Registered Nurses. You may be familiar with a Nurse Practitioner in your doctor’s office. He or she has, at a minimum, a master’s level of education and specialization in any number of pediatric and adult fields of health. The Rheumatology Nurses Society is currently working with the American Nurses Credentialing Center to establish a specialization certification in rheumatology nursing. This will be the first offering of its kind for rheumatology nurses to receive recognition in this important specialty.

A nurse is not an assistant and a medical assistant is not a nurse. A nurse is your advocate, a partner in your care. Find and get to know your rheumatologist’s nurse. Rheumatology nurses love their profession and care for their patients. Get to know the many roles your rheumatology nurse can perform on your healthcare team.
### 10 Tips for a Productive Doctor’s Appointment

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<td>Prepare</td>
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<td>Buddy-Up</td>
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<td>Bring</td>
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<td>Receive</td>
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<td>9</td>
<td>Reconnect</td>
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<td>10</td>
<td>Network</td>
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### Table 1

<table>
<thead>
<tr>
<th>&quot;Nurse&quot;</th>
<th>Registered Nurse -RN</th>
<th>Advanced Practice</th>
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<tbody>
<tr>
<td>Collaborative or Independent Nursing Practice</td>
<td>Post-Doctorate Certificate</td>
<td>Post Doctorate Certificate</td>
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<tr>
<td></td>
<td>Doctoral Level Registered Nurse</td>
<td>Doctoral Level Registered Nurse</td>
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<tr>
<td></td>
<td>PhD - Doctor of Philosophy in Nursing</td>
<td>PhD - Doctor of Philosophy in Nursing</td>
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<td></td>
<td>DNP - Doctor of Practice in Nursing</td>
<td>DNP - Doctor of Practice in Nursing</td>
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<td>Post Master's Certificate</td>
<td>Post Master's Certificate</td>
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<td>Master's Degree Level qualifies to take and MUST Pass Certification Examinations in Specialty Areas</td>
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<tr>
<td></td>
<td>Master's Level Registered Nurse</td>
<td>Master's Level Registered Nurse</td>
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<td></td>
<td>MSN - Master of Science in Nursing</td>
<td>MSN - Master of Science in Nursing</td>
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<tr>
<td></td>
<td>NP - Nurse Practitioner</td>
<td>NP - Nurse Practitioner</td>
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<td></td>
<td>CRNA - Certified Registered Nurse Anesthetist</td>
<td>CRNA - Certified Registered Nurse Anesthetist</td>
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<td></td>
<td>CNS - Clinical Nurse Specialist</td>
<td>CNS - Clinical Nurse Specialist</td>
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<td>CNM - Certified Nurse Midwife</td>
<td>CNM - Certified Nurse Midwife</td>
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### Table 2

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<tr>
<th>&quot;Nurse&quot;</th>
<th>Registered Nurse -RN</th>
<th>Basic Entry-Level</th>
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<tbody>
<tr>
<td>Collaborative or Independent Nursing Practice</td>
<td>Entry-level Degree qualifies to take and MUST Pass &quot;NCLEX- RN&quot; to become a &quot;Registered Nurse&quot;</td>
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<td>Entry-Level Registered Nurse</td>
<td>Entry-Level Registered Nurse</td>
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<td></td>
<td>BSN - Bachelor of Science in Nursing</td>
<td>BSN - Bachelor of Science in Nursing</td>
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<td></td>
<td>ADN - Associate of Science in Nursing</td>
<td>ADN - Associate of Science in Nursing</td>
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<td>Diploma in Nursing</td>
<td>Diploma in Nursing</td>
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<td></td>
<td>Entry Level Degree qualifies to take and MUST pass &quot;NCLEX - PN&quot;</td>
<td>Entry Level Degree qualifies to take and MUST pass &quot;NCLEX - PN&quot;</td>
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<tr>
<td></td>
<td>Entry-Level Licensed Practical or Licensed Vocational Nurse</td>
<td>Entry-Level Licensed Practical or Licensed Vocational Nurse</td>
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### Assitive Health Care

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<td>Levels of Healthcare Practice Assistance</td>
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<td>Two levels of Nationally Recognized Certifications</td>
<td>Two levels of Nationally Recognized Certifications</td>
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<tr>
<td>Certification Programs</td>
<td>Certification Programs</td>
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<tr>
<td>CNA - Certified Nursing Assistant - Certified by NNAAP?</td>
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<tr>
<td>MA-C - Medication Assistant Certification - Certified by MACE?</td>
<td>MA-C - Medication Assistant Certification - Certified by MACE?</td>
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<tr>
<td>Assistive-Level non-licensed/non-certified</td>
<td>Assistive-Level non-licensed/non-certified</td>
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<tr>
<td>Medical Office Assistant/ Medical Aide/ Medical Scribe ( any number of names used to describe an assistive medical role without licensure or certification.</td>
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* NCLEX - RN = National Council Licensure Examination for Registered Nurses, NCLEX-PN = National Council Licensure Examination for Practical Nurse. Passing allows the individual to practice nursing, granted by the state where the individual met the educational and clinical requirements.

* NNAAP = National Nurse Aide Assessment Program, MACE = National Medication Aide Certification Exam

* Sheree C. Carter, PhD, RN is Assistant Professor at Capstone College of Nursing at the University of Alabama, and President of the Rheumatology Nurses Society.
On March 21st 2015, the Spondylitis Association of America hosted a free Spondylitis Educational Seminar in the Los Angeles area. We welcomed friends - old and new, in Altadena’s beautiful Country Club on a sunny Southern California day; we learned much from our esteemed speakers who presented the latest in their fields, had great conversations with members, and, in a first for SAA, broadcast the entire program online for the world to see!

We hope you were able to join us either in person, or online. We had a full house at the live event and over 800 unique devices logging in to view the presentations online. We enjoyed interacting with our live audience in person, as well as with our virtual audience through various Social Media channels. You will see some of the comments we received from our online audience in our letters section, on Page 3.

If you missed the program, here is a quick recap for you: SAA's Richard Howard emceed, and kept things engaging for all. In fact, pay close attention to Richard at the start of each section..... There is a private joke none of us here on staff caught until after the program had concluded. Can you find it?

Rheumatologist David S. Hallegua, MD presented on Spondyloarthritis treatments and the latest research; Physical Therapist Sturdy McKee, MPT had the audience up on their feet as he demonstrated stretches and underscored the importance of regular exercise to maintain mobility (and he should know – not only is Mr. McKee a wonderful Physical Therapist, he also happens to be living with spondyloarthritis himself.) Our final speaker of the day, Ophthalmologist Olivia L. Lee, MD taught us much on Iritis/Uveitis and discussed treatments for complications.

We thank our presenters for sharing their expertise and valuable time with us and, as always, our members and supporters. These programs would not be possible without YOUR involvement and support and for that – you have our deepest gratitude.

The presentations have been archived, and are now available to view online on SAA’s website. We hope you find the information valuable!
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She can’t drive yet - but she can use your car

Kids get spondylitis too. Donating an unwanted vehicle to SAA will help ensure that they have the resources they need to live life to the fullest, in spite of the disease. The process is quick, includes free pick-up or towing - and best of all - the proceeds go to improving the lives of spondylitis patients of all ages. The vehicle doesn’t even have to run and you’ll get a great tax deduction for your donation!

Contact Helene Hart at 1-800-777-8189, ext. 229 or at hhart@spondylitis.org.