I’ve got a secret!

Well, I certainly picked an exciting time to join SAA! These past eight months have flown by in a flurry of activity and I know there are even busier times to come!

My first day on the job found me rubbing elbows with the top tier global experts in the field at the “Spondyloarthritis 2017: Unmet Needs Conference III” in Bethesda, MD where I was immediately immersed in the hardcore science that makes SAA a leader in advancing our understanding of SpA. Talk about jumping in with both feet!

Almost before I could catch my breath, we were off to a whirlwind week of meetings and scientific sessions at the American College of Rheumatology’s Annual Scientific Meeting in San Diego, CA, where we also held a meeting of our Medical & Scientific Advisory Board and presented a Patient Educational Seminar.

In February we exhibited at the PriMed Conference in Florida to help educate Primary Care Physicians to recognize the signs of spondyloarthritis, and to know when to refer to a rheumatologist.

April (Spondylitis Month!) wrapped up in Denver where we presented a Patient Educational Seminar on Saturday and held a Support Group Leader Conference on Sunday for 32 of our volunteer group leaders. From there I flew directly to DC for a busy few days of networking on behalf of the people we serve.

While I was in DC, some of our staff flew to Las Vegas for a Media Day in association with Dan Reynolds and This AS Life Live! Just days later, we were reunited in Boston for the SPARTAN meeting where more cutting edge science was revealed.

Next month, we’ll be presenting a poster at the EULAR meeting in Amsterdam with the results of our third Spondyloarthritis Life Impact Study.

These are amazingly robust and exciting times for your SAA. And not one bit of it would be happening without the dedication and support of members like you.

And there’s so much more on the schedule. (Including something really special that we’ll pilot in 2019 and will take the SpA world by storm in 2020. But it’s a secret and you won’t get a word out of me. Yet!)

In the meantime, I’m looking forward to meeting all the wonderful opportunities that have been presented and to creating more along the way. There’s so much exciting work to be done. In fact, I’m off to Houston tomorrow for another PriMed Conference and I’ll also get a chance to attend the Houston Support Group meeting on Saturday. After that, I’ll meet with some of our key volunteers and grassroots organizers in the area.

But first I really need to do some laundry!

Cassie
“I’ve just received the 35th Anniversary edition of the SAA’s magazine and read the ‘SAA Turns 35! How Did We Get Here?’ article, which brought tears to my eyes remembering the many years my husband and I were involved with the organization. We were among the organization’s first 35 or 50 members! Having served on the board as Secretary for several years prior to relocating to Florida, I’ll tell you how we got here - with the hard work and dedication of so many volunteers and dedicated staff like Jane Bruckel.

Jane was the force that drove us to distraction when it came to developing a mission statement. I thought I would go mad before one was conceived, but it was this type of dedication to perfection that led the way for everything the organization has accomplished through its first 35 years. I was at that support group meeting, yes the first meeting.

In any event, the article brought tears to my eyes as I remembered my own involvement with ASA [Ankylosing Spondylitis Association], and now SAA, and the joy my volunteer work brought me. I have volunteered with other organizations over the years in California and Florida, but none was as rewarding as SAA.

Thank you all, staff and volunteers, current and past for making the organization what it has become. The future can only be brighter, and bring ever closer within our reach the hope of a cure.”

~ Karel Thurston
Tellico Plains, TN

Editor’s Note: What a pleasure it was to read your note, Karel! Our founding members hold so much of our history, and we wouldn’t have come so far without their (your) dedication and resolve. Thank you for your decades of support. You might be interested to know though that you weren’t one of the first 35 or 50 members. You were actually number 12! The typewriter-written first membership roster from 1983 is now worn, brown, and slightly ripped, but it is maintained as a founding document of sorts.

A Correction: Our previous, 35th anniversary issue included images from SAA’s Unmet Needs Conference III on pages 13 – 15; however we neglected to credit the photographer responsible for them. Our apologies to the talented Barbara Alper of Barbara Alper Photography who was responsible for the wonderful photojournalistic coverage of the event.

Barbara Alper is a New York based full-time editorial and fine art photographer with multi-faceted documentary, conceptual, and narrative portfolios. She has exhibited her work internationally, and published editorial photos in many distinguished journals, magazines and newspapers, such as Barron’s, Newsday, Newsweek, and Time, including a lengthy association as a news and feature photographer with The New York Times. She has a large body of historically important editorial images associated with the Getty Images-Archives. To learn more about her work, please visit barbaraalper.com.

LETTERS TO THE EDITOR
We want to hear from you! Send your thoughts, questions, opinions, and rebuttals.

Please send letters to:
Elin@spondylitis.org
Letters to the Editor/SAA
16360 Roscoe Blvd, Suite 100
Van Nuys, CA 91406

Please note that we reserve the right to edit for space and clarity.
People with Spondyloarthritis (SpA) know very well that their bones and joints hurt in areas around the body (called “enthesitis”) often in places that are subject to pressure from daily activities such as sitting, walking, or standing. Over the years researchers have tried to understand what causes these problems, and it was only recently with advances in imaging (such as MRI and ultrasound), studies in animal models of SpA, as well as in genetics that a clearer picture exists as to what this is. Although we do not know precisely what causes it (we do have theories) or exactly how to treat it (the biologic drugs help), we are getting close to a better understanding of what it is exactly. Insertions of tendons and ligaments into bone are called entheses; it is here - where the hard and soft tissues meet - that represent areas of concentrated physical stress, and sites of repetitive biomechanical impact.

Insertions of tendons and ligaments into bone are called entheses; it is here - where the hard and soft tissues meet - that represent areas of concentrated physical stress, and sites of repetitive biomechanical impact.

Researchers have shown, predominantly in animal models of SpA, that these areas, when stressed, create an inflammatory cascade of cytokine production with infiltration of inflammatory cells into the surrounding structures. Additional data collected in these studies do show that adjacent bone tissue reacts as if it is repairing an injury and subsequently produces new bone just as if a fracture had occurred. Understanding the pathways that are involved in these relationships (inflammation, injury, repair, etc.) is the subject of current research efforts both in humans and in animal models. It does appear that not only mechanical forces, but genetic predisposition also plays a role.

With the use of advanced imaging techniques in patients with SpA we are learning, for example, that these same factors may also play a role in the spinal damage that occurs in AS. There might be certain areas of the spine that are subject to more stresses than other areas, and these situations may lead to the advanced bone changes in the spine that we see in more severe disease. Finally, the concept of “enthesitis” is being linked to outside or environmental triggers such as certain bacteria residing in the gut which, in some patients genetically predisposed, can produce these unwanted features of the disease. Since “enthesitis” can occur in patients with inflammatory bowel disease (who already have an abnormal intestine structure), we are learning more about why it might occur in SpA.

Not surprisingly, there have been attempts to treat enthesitis with agents that block the cytokines that are felt to play a role in the condition, such as TNF, IL-22, IL-17, and IL-23. Preliminary work in this area is promising but more needs to be done. A more complete role for biomechanical stress and genetic predisposition awaits additional data from safely applied new imaging techniques as well as advances in gene sequencing and discovery.

Did You Know?

Enthesitis can occur in IBD (Inflammatory Bowel Disease) patients who do not have spine or sacroiliac joint involvement. Though we don’t have complete information on how often this occurs, some studies have shown a very high prevalence of ultrasound abnormalities in those with IBD. This area is incompletely studied and in need of further investigation.

Many strides have been made in the areas of diagnosis and treatment, but there is much more that needs to be done. Spondylitis Awareness Month continues to serve as a critical opportunity to raise awareness of the disease within both the medical community and the general public.

“Every April since 2009, SAA has been observing Spondylitis Awareness Month as part of our ongoing efforts to draw national attention to a potentially debilitating disease that is often undiagnosed or misdiagnosed.”

Every April since 2009, SAA has been observing Spondylitis Awareness Month as part of our ongoing efforts to draw national attention to a potentially debilitating disease that is often undiagnosed or misdiagnosed. Our goals include emphasizing the need for recognizing the symptoms of spondylitis for proper diagnosis, funding research for a cure, and providing support programs that educate and empower individuals impacted by the disease.

During the month of April 2018, SAA initiated a series of activities to drive awareness through a multi-channel campaign which included a toolkit for constituents to request official Proclamations of April as Spondylitis Awareness Month by their Mayor, and a pledge to distribute key messages through social media.

“SAA received signed proclamations from the Mayor of Los Angeles and several smaller municipalities.”
SAA received signed proclamations from the Mayor of Los Angeles and several smaller municipalities.

In our ongoing efforts to raise awareness of spondylitis within the general public and medical community, we also initiated an OOH (Out-of-home) advertising campaign. Clear Channel Outdoor is one of the world’s largest outdoor advertising corporations and offers services within 43 of the largest 50 U.S. DMAs (Designated Market Areas). Clear Channel Outdoor generously provided SAA with advertising on Billboards, Transit Shelters, and Digital Displays at a significantly reduced charge within the Greater Los Angeles market. As part of this campaign, we also included SMS (Short Message Service) text codes to measure engagement with select keywords (SpondyWhat, ThinkSpondy, SpotSpondy).

We also promoted Season 2 of ‘This AS Life Live!’ videos. These awareness videos are a collaboration between SAA, Novartis Pharmaceutical Corporation, and the host Dan Reynolds, an AS patient and lead singer of Imagine Dragons. The goal of the series is to inspire and encourage people to live their best lives with AS and to raise awareness of the disease.

On social media, we provided supporters with covers for Facebook and Twitter to post to their social accounts. Themes included awareness of spondylitis signs & symptoms, diversity segments, and specifically for Primary Care Physicians – knowing when to refer to rheumatology.

We also created personas and writing prompts in which we asked social media followers to submit stories around characters and prompts and share them on their social accounts. Since many people living with spondylitis experience challenges of pain disrupting their ability to get a good night’s sleep and proper rest, this prompt tied in well with the Painsomnia episode of ‘This AS Life Live!’ with AS patient and guest Dawn Gibson.

Editor’s Note: Have you seen this wonderful episode yet? You’ll find it on our website at spondylitis.org/Community/Living-with-Spondylitis

The Traditional SpA Classification System recognizes six disease types: Ankylosing Spondylitis (AS); Psoriatic Arthritis (PsA); Enteropathic Arthritis (EnA); Reactive Arthritis (ReA); Undifferentiated Spondyloarthritis (USpA); Juvenile Spondyloarthritis (JSpA). We highlighted several of these during the month.
Key messaging for this year was geared toward educating the front line medical community on recognizing the symptoms and knowing when to refer to rheumatology; emphasizing that the disease is not restricted to only certain ethnicities or genders; the importance of funding research; and empowerment for those who are living with the disease.

Spondylitis Awareness Month was first championed in 2009 by Michael Smith - an SAA lifetime member, tireless patient advocate, and creator of the beloved Spondyville website.

Spondylitis Awareness Month was first championed in 2009 by Michael Smith - an SAA lifetime member, tireless patient advocate, and creator of the beloved Spondyville website. Although Michael passed in December of 2016, his voice and advocacy efforts are still reflected and echoed within SAA’s annual awareness campaigns and within the spondylitis community at large.
As part of SAA’s ongoing mission to expand horizons in spondyloarthritis research, we hope to encourage and support new, upcoming rheumatologists and researchers in advancing spondyloarthritis research.

The SAA/Bruckel Early Career Investigator Award, created in 2001, recognizes outstanding “contributions to the care and understanding of patients with spondyloarthritis.” The award winner receives a $20,000 grant from SAA to use in spondyloarthritis research. The annual award is usually given to just one investigator; however, on rare occasions when the competition is too tough, SAA awards multiple $20,000 awards. This was one such year.

We recognize the numerous contributions of, and introduce our readers to, Drs. Kristine Kuhn and Maureen Dubreuil.

Dr. Kristine Kuhn obtained her MD and PhD at the University of Colorado Health Sciences Center. There she developed her interest in rheumatology while working on her PhD in arthritis. After graduating medical school, Dr. Kuhn moved to St. Louis, MO to complete her residency in internal medicine and fellowship in rheumatology at Barnes-Jewish Hospital and Washington University. During this training, Dr. Kuhn observed many challenges that individuals face in the diagnosis and treatment of spondyloarthritis. Therefore, she began to focus on this topic in her research and clinical activities when she returned to Colorado as a faculty member in 2013 to start her own research program.

“Research has shown that 30-50% of patients with spondyloarthritis will develop bowel inflammation and about 50% of patients with IBD develop disease outside of the intestines that affects their eyes, skin, and joints.”

**Spondylitis Plus**: Please tell us a bit about your general research focus, your recent work, and what you are most excited about in SpA research.

**Dr. Kuhn**: “My clinical and research interests are related to spondyloarthritis with a special emphasis for those with overlapping Inflammatory Bowel Diseases (IBD). Research has shown that 30-50% of patients with spondyloarthritis will develop bowel inflammation and about 50% of patients with IBD develop disease outside of the intestines that affects their eyes, skin, and joints, which prompts consultation with a rheumatologist. Our recent work is looking at how gut bacteria develop local immune cells that traffic to the joints and initiate arthritis. We hope to identify these cells as a biomarker for disease as well as inhibit this trafficking for the treatment of spondyloarthritis.”

**Spondylitis Plus**: How will the SAA/Bruckel award help support your research?

**Dr. Kuhn**: “Medical research, in general, is benefiting from the development of some exciting new tools that allow us to investigate a large number of factors in a small piece of tissue or in blood. Support from the SAA/Bruckel award will allow us to utilize these technologies. Such work will allow more rapid advancements for spondyloarthritis.”
Maureen Dubreuil, MD, MSc
SAA/Bruckel Early Career Investigator Awardee
Assistant Professor
Boston University School of Medicine
Department of Clinical Epidemiology Research and Training

Dr. Maureen Dubreuil is a rheumatologist and researcher at Boston University and the Boston VA. Her research focuses on complications of spondyloarthritis and side effects of treatment. In addition to her research, Dr. Dubreuil is working to educate the next generation of doctors on evaluating patients with back pain, and caring for those with spondyloarthritis. For the past two years, she coordinated a symposium for doctors in training as part of the annual meeting of the Spondyloarthritis Research and Treatment Network (SPARTAN). She is involved in developing treatment guidelines for Axial Spondyloarthritis through the American College of Rheumatology/SAA combined initiative.

Spondylitis Plus: What have been your areas of focus in spondyloarthritis? Please tell us a bit about your recent work, and what you have coming up on the horizon.

“ One theme of my work is heart disease in spondyloarthritis. I led a study that examined the risk of heart attacks with non-steroidal anti-inflammatory drugs (NSAIDs) in spondyloarthritis patients. ”

Dr. Dubreuil: “One theme of my work is heart disease in spondyloarthritis. I led a study that examined the risk of heart attacks with non-steroidal anti-inflammatory drugs (NSAIDs) in spondyloarthritis patients, using a large database from the United Kingdom. This study found that specific NSAIDs may increase risk of heart attacks to a greater degree in people with spondyloarthritis than those with osteoarthritis. I am studying this same topic in other populations, including a large database in the United States. I also collaborated on a study of the effects of statin (cholesterol medication) use in ankylosing spondylitis, finding that statins appear to have a more protective effect in people with ankylosing spondylitis than in the general population.

A second theme of my work is understanding patients’ preferences for treatments in spondyloarthritis. In 2016 I began work on a National Institutes of Health-funded project to assess factors that influence spondyloarthritis patients’ preferences for medications. In the coming year, I will begin work on a cost-effectiveness study, comparing different approaches to spondyloarthritis treatment, such as starting with an NSAID versus starting with a biologic medication. I am also involved in the VA-based spondyloarthritis registry, called Program to Understand the Long-term Outcomes in Spondyloarthritis.”

Spondylitis Plus: How will the SAA/Bruckel award help support your research?

Dr. Dubreuil: “I am incredibly grateful and honored to be awarded the SAA/Bruckel Early Investigator award. I will use these funds to reach more patients for studying medication preferences, and to share study results at national and international scientific conferences.”

Editor’s Note: You can learn about our past awardees, as well as about SAA’s involvement in research, on our website at spondylitis.org/Research.
SAA hosted a free Spondylitis Educational Seminar in Denver, CO on April 28, 2018, livestreaming and recording the full program for those who couldn't attend. Our speakers were Rheumatologist and Researcher Liron Caplan, MD PhD and Clinical Health Psychologist Jana Bolduan Lomax, PsyD. The Program was supported in part through educational grants by AbbVie and Novartis. We are including highlights from the in-depth Q&A session with Dr. Caplan.

Recordings of both presentations are available on SAA's website, at spondylitis.org/Seminars-and-Webinars

**Q:** As a mother of two girls, 10 and 12, who have not been diagnosed -- and I’m terrified to get their blood work done, I wondered if you have any advice. I know we’re still looking for early diagnosis but in terms of prevention … let’s look at it environmentally for them. I know we went through a chemical clean out of our house, we stopped using chemicals. We’ve looked at diet. I’m just trying to do everything I can now to keep them in a pre-clinical phase and any advice you have would be super helpful.

**Dr. Caplan:** This is an area of intense study in rheumatoid arthritis. At the university, we’ve had studies going on for 20 years, looking at the pre-clinical disease and looking at the exposures. The amount of data that we have is just overwhelming with evidence suggesting that there might be hormonal triggers, there might be … and again, this is for populations. I’m not talking about individuals because we certainly don’t have data that can get down to that point.

Smoking is a huge risk factor in rheumatoid arthritis. There are all sorts of risk factors that have been identified in this very different disease and we don’t even have those associative studies yet, much less being able to target individuals and tell them. The simple answer is we know that smoking in some studies relates to disease activity and severity in some of the more closely related diseases to axial spondyloarthritis. Does that mean that it also has a role in the early stages? I don’t know the answer to that.

I would simply say … Here are two pieces of advice: I would say, the first thing is statistically speaking, even with a first degree relative - someone else in the family who has AS - they’re still more likely not to have the disease than to get the disease. That’s something. And then my second piece of advice around that is to not live in fear; for them to live as if they’re not going to get the disease.

And live healthy. Tell them to live large and live healthy. That’s unfortunately all we can do right now until the types of studies that I mentioned right at the beginning of my talk are done where we look at pre-clinical disease, we look at folks at risk, we follow them for a time. These things, again, in rheumatoid arthritis, they’ve got a 20 year lead on this from what we have here and so these studies take years to do but hopefully, with the folks in this room, we’ll get there.

**Q:** Do people run the risk of relapse when they stop biologics, once they’re stable?

**Dr. Caplan:** That is a really great question. So the question was, whether folks who stop biologic treatment … and I assume you’re talking about TNF inhibitors, do they relapse. Yes, there has been a study actually and a number of trials and it looks like roughly about 85, 90% of folks, when they go off of the TNF inhibitors completely, do relapse at some stage. I think the modality that’s probably more promising is instead of cutting off the therapy all together is
just tapering, and that looks like, that’s a more successful therapy. We will be looking at that very question with the axial SpA treatment guidelines update coming out this year and giving more specific advice.

“There’s a lot of indirect evidence that there is this interaction between the gut and the foreign bacteria that reside there, and our immune system.”

Dr. Caplan: We’re just at the initial discovery stages, there’s not a lot that we can recommend or tell patients. We’re sort of just starting to ... our eyes are getting acclimated to the dark and we’re starting to see some very rudimentary shapes.

There’s a lot of indirect evidence that there is this interaction between the gut and the foreign bacteria that reside there, and our immune system. There’s this very complex interplay with immune cells being exposed to proteins in the gut and in trafficking to other areas of the body, other areas of the immune system. There’s the clinical demonstration that up to 50% of folks with axial spondyloarthritis at some stage in their life will have inflammation, at least on a microscopic level, in the gut. That’s if you just go in and blindly biopsy folks; but when you look at what’s going on clinically, what the physicians are actually diagnosing, that rate is at 7%.

So, 7% of folks with axial spondyloarthritis actually have obvious inflammatory bowel disease. My suspicion is that there’s this low level tiny inflammation that’s going on in the gut in a lot of folks, and it’s probably having some interaction with the immune system but we don’t know the degree to which that’s really important and we certainly don’t have any evidence that doing anything to the gut is going to alter disease long term. There’s clearly something going on there and we just don’t know what to do.

Q: If your disease is well controlled on a biologic, is there data on whether you’re still likely to fuse, or for your disease to get more severe? Or is the medication controlling it so it won’t get to that point?

Dr. Caplan: That’s a really good question. There isn’t randomized control trial data and the reason is because no one runs a randomized control trial for years - which is ideally what you do, a minimum of two years if it was in a very large population - to show the kinds of difference whether the TNFs actually are inhibiting radiographic progression. What we have to do then is look at patients who are on these therapies, control for as many things as we can in their differences, and then look statistically to see whether those that were on the therapy have different rates of progression. This has been looked at, at least twice, once in a European study and then once by my predecessor in SPARTAN, Lianne Gensler, who is handing me the gavel this week, and her colleagues.

The observational data - the non-randomized control data that came out of Lianne’s group - suggest that there is a protective effect on folks who get started on TNF early enough. In other words, you’re not waiting 10 years to start your TNF and you get it for long enough. That’s not surprising because you need to allow for enough time that the inflammatory lesions move from inflammation to the fatty metaplasia to the bony growth before you can show those differences and that takes years. If you’re on it for long enough and you started early enough, at least the observational data suggest that there might be a protective role from TNF.

That’s by no means the final word and we need to see more data around that before we feel comfortable in making that statement.

I follow the radiographs, x-rays every two years and if the symptoms are doing well, then I think it’s unlikely that someone is ... I feel reasonably assured knowing that a person is on that long term, that we are actually preventing damage and disability. There’s not a ton of data I can point to for that but that’s been my impression.
Looks like an ordinary business card, right? But actually, for many, it can make a difference in their lives.

Hi, I’m Sean and I’ve been with SAA for almost a year now. It’s been my great pleasure to interact with hundreds of people like you, every month, who use the information on this card to reach out to SAA for information, direction, guidance, or support.

The inquiries run the gamut, from simple things like, “Can you help me find a rheumatologist in the Cleveland area?” to complex issues like navigating the social security disability process. Every call or email is different, and every one helps us improve our understanding of what we can do to aid the spondylitis community in real and meaningful ways.

Want to join SAA or renew your membership? Or make a donation in honor or memory of someone special? Maybe you’re interested in putting on a volunteer fundraiser? I can help with that!

“Your call is important to us. Please listen carefully as our menu options may have changed.” That’s something you won’t hear when calling SAA. Because our phones are answered, Monday through Friday, 9 - 5, by an actual person who can help or will quickly connect you to the person who can. (I can’t tell you how often the person on the other end of the call is flustered when we pick up!)

“In large part, SAA’s strategic plan is dictated by our members. We listen. We learn. And we respond.”

And emails are answered within 24 hours, or sooner in most cases, not with an automated response but by someone who wants to help you get the answers you need.

Why? Because we actually want to speak to our members. Listening to your stories, your experiences, and your questions helps us determine what resources we need to develop and what programs we need to offer going forward. In large part, SAA’s strategic plan is dictated by our members. We listen. We learn. And we respond. I really hope to hear from YOU!
AND SOMETIMES WE CALL ON YOU!

We’re only able to adapt to the needs of the community because of the generous financial support from members like you. That’s why your yearly membership fees are so important.

But SAA provides many more programs and services than those covered by the membership fee. In fact, membership fees each year account for less than 5% of our operating budget.

That’s why SAA recently mailed you our Spring Appeal letter. Our three yearly gift appeals help to raise the money that can be put to work funding the programs and services that cannot be covered by membership fees alone.

If you’ve already responded with a gift, please accept our most sincere thanks. If not, your tax-deductible gift today will be put to work to maintain -- and expand -- the wide menu of programs necessary to inform, educate, and support the spondylitis community and the physicians who serve them.

So, if you believe that it’s important for SAA to continue to be able to respond to the needs of the community it serves, there are two things you can do today – call or email to let me know how we can help you, and make a donation while our Spring Appeal is still going on. You can do so with the confidence that SAA will put your donation to work responsibly and with the specific needs of the spondylitis community in mind.

Thanks and I hope to hear from you soon!

Calling all artists!
We know you’re out there!

We’re currently taking submissions of original artwork by SAA members to feature in a “member calendar” for 2019. The theme of the calendar is artist renderings of our logo.

There are just a few simple guidelines:

- The SAA logo should be recognizable in your piece, and it cannot be political or religious in theme, styling, etc. The submission date for art is August 31, 2018.

- Our logo can be altered and reimagined - the creativity is up to you! The medium of the art is also wide open (glass, needlework, photography, collage, watercolor, etc.) SAA will showcase approved artwork in our national office in Los Angeles as well as in the member calendar and through social media.

Please contact Sean at 818-855-2106 or sean.ewert@spondylitis.org for more information.
It is well established that physical therapy and exercise are mainstay treatments in the management of spondyloarthritis. In general, it is recommended that patients participate in disease education programs, exercise on a regular basis, stop smoking, and participate in a home exercise program. Physical therapy intervention is also recommended. The American College of Rheumatology recommends active therapy interventions (performed by the patient) over passive interventions (administered by the physical therapist), and land based interventions over aquatic exercise (due only to convenience and availability issues involved with aquatic exercise.) They strongly recommend against undergoing spinal manipulation.

What do all these recommendations mean for the typical SpA or sports? What should your expectations be when you are looking for a physical therapist, and what treatment programs should you expect?

A regular exercise program, ‘above and beyond activities of daily living,’ is essential for most adults.

The short answer: There is no single exercise program or physical treatment that has been demonstrated to be superior to another specifically in SpA. The exercise guidelines are derived from the American College of Sports Medicine (ACSM). These state that the benefits of exercise outweigh the risk in most adults. In fact, the guidelines are similar across most disease conditions such as cardiac, diabetes, and osteoporosis. A regular exercise program, ‘above and beyond activities of daily living,’ is essential for most adults. This means participating in activity above and beyond your normal routine of waking up, dressing, going to work, walking around at work etc.

The recommendation is participating in 150 minutes per week of moderate intensity cardiovascular exercise, a program of resistance exercise of all the major muscle groups, flexibility exercise more than twice weekly, and neuromotor exercise that incorporates balance, agility and coordination. This amounts to 20-30 minutes per day of cardio workout with a target heart rate of 55-90%. For more details, you may read the full ACSM position paper.

If this seems impossible to fit into your busy schedule right now, here is some hope! There is scientific literature suggesting that moderate intensity walking may be comparable to swimming in many of the AS specific outcome measures that were looked at. An easy way to squeeze in your exercise break during the work or school day is to use a Fitbit or Apple watch and take a 20-30 minute brisk walk (targeting 70% heart rate) around the block or track during your lunch break.

Finding a physical therapist who can guide you through all of this may be challenging, but is ideal and more than worth it in my opinion. Depending on where you live, access to physical therapists with expertise in the management of SpA, and availability of funding/resources to visit them may all be considerations. In this case it is important to find a physical therapist that you are comfortable with and willing to build a therapeutic relationship with over a long period of time. All of the recommended guidelines and exercise prescription discussed above can be overwhelming when you are dealing with a chronic illness, daily work/life, and multiple medical recommendations made by your rheumatologist. I strongly recommend a gradual approach to implementing your exercise program with a target of incorporating all the exercise elements over the course of 12-18 months. You may need to start with a few weekly visits to your physical therapist so you can together craft your individual exercise program, followed by visits once every few months for evaluation and modification of the exercise program. Think of your physical therapist as your ‘lifelong wellness and fitness expert.’ For those of you interested in further reading I would recommend a paper by J. Millner et al. in Seminars in Arthritis and Rheumatism 45 (2016)411-427, titled ‘Exercise for Ankylosing Spondylitis: An evidence-based consensus statement.’ This lays out an excellent framework for what to expect and perhaps request from your physical therapist when prescribing exercise in SpA.

And now…get up and take a brisk 20-minute walk as reading this article doesn’t count as exercise!
The Philip Donlay Guest Column:

Are You Sure It's Just A Flare?

I was diagnosed with ankylosing spondylitis nearly 12 years ago, and like so many of us, I dealt with this diabolical disease for years before I ever heard about AS. I’ve had flares; we all have. For me, the paralyzing fatigue comes first. Followed by the aches and chills that feel like the beginning of the flu. As the pain builds, there’s really nothing in my arsenal to combat what’s coming next. It’s the worst, and my typical flare drives me to bed where I’ll lay for hours, or days, completely at the mercy of my own immune system. I’m now in far greater touch with my body, what sets off pain, and what doesn’t. I’ve developed a pretty good feel for what I need to do to keep my muscles and joints moving without inflicting damage. I see my doctors regularly, and I listen to what they tell me. After all these years I thought I’d come to understand the complexities of this affliction, and what I could expect on any given day, week, or month. I can always predict a flare long before it levels me. Or so I thought.

This story starts in Victoria, British Columbia. As a novelist I can work virtually anywhere and part of my annual migration is to depart the mountains of Montana, and travel to coastal Canada to avoid the early blizzards in the Rockies. I’d settled in, had been working for several weeks and was well into my daily routine. I work some, move about often, and stretch all the time to fight the inevitable stiffness. In the middle of the afternoon I try to get out of the condo and take a walk. My smart phone has me zeroed in on the 3,500 to 4,000 steps per day range that I’ve found to be optimal for me. Everything seemed stable and my overall pain levels were what I’d describe as normal.

One Friday evening, a day like any other, I fixed a salad for dinner, watched television, and then went to bed to read. I eventually switched off the light, rolled on my side and a sudden pain erupted in the left side of my chest. Startled, I moved to my back expecting relief, but my chest pain got worse. I got out of bed as the pain quickly became unrelenting. I travel with opioids that I rarely take, but I didn’t hesitate a second as I took them.

I’ve suffered from chest pain before, and I’ve heard doctors use the word Costochondritis to describe the condition. My previous attacks were painful, linked to a flare, and seemed to be movement related. I’d never experienced anything like this out-of-the-blue attack. Nevertheless, out of habit, or just plain foolishness, I diagnosed what was happening to me as an AS event. It wouldn’t be the first miserable night I’d spent in pain. Maybe I momentarily considered other reasons for the pain, but the obvious enemy was AS; I’d been here before. As I continued to analyze and battle my situation, the pain only intensified.

I have a theory that AS patients, people who’ve sometimes spent years being misdiagnosed by others, are often hesitant to reach out for help. We’ve witnessed at times spectacular inaccuracy, or even perceived indifference within a broad range of the health care system. Taking the lessons learned from those experiences, there is a tendency for us to become more proactive than reactive. We are almost forced into the role, so we become our own doctors. I could feel the opiates enter my system, and while they were ineffective against the pain, the message I should have received was that I was now self-medicated. I had accomplished nothing except impair my own judgment as the pain grew worse.
It hurt to sit, and to lay down, so I slowly paced the condo trying different positions to ease what had turned into what I was now calling a “super-flare.” I drew water for a hot bath to try and find relief. In agony, I could hardly move in and out of the tub. The water did nothing, and the pain pills were in no way up to the job at hand. The next phase happened fast. With no warning, I bent over and completely emptied my stomach. I’d never before gotten physically sick from a flare, and I recalled a small fact I’d learned in my now ancient CPR training: People in life or death situations often vomit. Its nature’s triage, the body telling you you’re going to need all of your energy to stay alive, and it’s not the time to waste precious energy on digestion. Properly scared as well as confused, I managed to make one of the few correct decisions of the evening. I did what I should have done ninety minutes earlier. I called the front desk and told them I was having chest pains and that I needed an ambulance.

As quick as that I was no longer in control. I’d passed myself off to others. The landline rang and a calm female voice began asking questions. She asked about my meds, when this started, and what I’d been doing since the pain started. In the distance I could finally hear a siren. They were coming. Miserable, I made my way to the door and propped it open for my guests. The second they arrived it was all business, and within minutes I was on a gurney headed out of the building. There are no windows in the back of an ambulance, so of course I had no way to know exactly where I was being taken. At that point I’m not really sure I cared.

I was rolled from the ambulance down a hallway past a waiting area, and whisked into a curtain draped cubicle. I was tagged, vitals were taken, blood was drawn, and an IV started. I felt very detached, only an interested spectator at this point. The labs came back and they were able to rule out a heart attack. They shifted gears and a nurse hurried in and gave me two injections of some kind of nonsteroidal anti-inflammatory. The medicine was administered in two doses, ten minutes apart via my IV. She waited with me. Within minutes of receiving the second dose, the pain ebbed and was completely gone within thirty minutes. Free from the pain, and exhausted from both my mental and physical punishment, I fell asleep.

At some point they woke me up, took another round of vitals and I was released and taken to a small deserted lobby. It was still dark outside. The nurse pointed toward a direct dial phone on the wall and explained that it would connect me directly with a taxi service. The phone rang and the dispatcher informed me a cab would be sent to the Royal Jubilee Hospital. I hung up. At least I finally had a name for the place I’d been taken and my brain was starting to connect the lost dots. Wherever I was, I was so very grateful for the people who had treated me.

As I waited for my ride, I began to sift through everything that had happened, and even more worrisome, what could have happened. I was relieved it had only been a flare, though a flare that reached new levels of pain - unwelcome news I’d ponder another time. I repeatedly chastised myself for being so hesitant to get help. What if it hadn’t been AS? It could have easily been something else. Just because we have this painful disease in no way exempts us from other afflictions. Being stubborn could have resulted in me being found in the condo, a sad casualty of having played both doctor and patient. Never again, I know enough to realize that pain and fear create instant anxiety, which does nothing but

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impair judgment. Throw in some opioids and you’re compromised without a sound decision to be found. I wasted a lot of time before reaching out. Please don’t hesitate to call for help. There are people out there, first responders, waiting to assist - and I can testify to the fact that they’re pretty good at their jobs.

*Editor’s Note:* We’d like to echo Mr. Donlay and stress to our readers to please reach out for medical help when in doubt, or when something just doesn’t seem right. [Trekmedics.org](http://trekmedics.org) has an international directory of Emergency and Ambulance services, should you experience an emergency while traveling. *Our thanks to Mr. Donlay for sharing his experience.*

Philip Donlay learned to fly at age 17 and was first published at 18. In the aviation world, success came quickly. Whether flying a Saudi sheik, nighttime freight, or executives of a Fortune 500 company, Donlay logged over six million miles while traveling the globe to 40 countries on five continents. After decades of unexplained pain, Donlay was finally diagnosed with ankylosing spondylitis, which eventually grounded him. Unable to fly, he turned to his second passion, writing, and is a bestselling novelist with eight published books. When he steps out of the world of fiction writing, Donlay is quick to share his insight into the ongoing battle he wages with AS. Currently, he divides his time between Utah and the Pacific Northwest.

You can learn more about, and contact Donlay through his website, [philipdonlay.com](http://philipdonlay.com) and through Facebook at [facebook.com/AuthorPhilipDonlay](http://facebook.com/AuthorPhilipDonlay). He loves hearing from readers and fellow spondylitis warriors. Look for additional stories from Donlay in the next few issues of *Spondylitis Plus.*
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