SpondylitisPLUS

FALL 2021

COMPLICATIONS AND COMORBIDITIES IN LONG-STANDING SPONDYLOARTHRITIS: PART 2

SAA'S COVID-19 AND SPA SURVEY

SAA VOLUNTEER HELGI OLAFSON GOES THE DISTANCE FOR SPA AWARENESS

YOUR STORIES: I WAS THE FAT KID

Spondylitis Association of America™
Serving the Spondyloarthritis Community

SPONDYLITIS ASSOCIATION OF AMERICA

16430 Ventura Blvd., Suite 300
Encino, CA 91436
Phone: (800) 777-8189
email: info@spondylitis.org
spondylitis.org

SAA MISSION

To be a leader in the quest to cure ankylosing spondylitis and related diseases, and to empower those affected to live life to the fullest.

BOARD OF DIRECTORS

HONORARY BOARD MEMBERS

SCIENTIFIC ADVISORS

CHIEF EXECUTIVE OFFICER

Cassie Shafer

CHIEF MISSION ADVANCEMENT OFFICER

Richard A. Howard, MBA

CHIEF PHILANTHROPY OFFICER

Diann Peterson, CFRE

SPONDYLITIS PLUS

Published four times a year
Elin Aslanyan, Editor-in-Chief;
Director of Programs
Rachel Zaimont, Managing Editor
Printing by Sundance Press, Inc.
All stock photography and illustrations
supplied by Shutterstock contributors

HOW CAN WE HELP?

SAA's staff and board of directors are sending our wishes for health and safety to you and your loved ones. Is there anything we can do to help? What are your needs? Reach out to us at **info@spondylitis.org**. Now, and always, you're on our minds and we are here for you.

SAA SPOTLIGHT:

Serving the Spondyloarthritis Community

The Merriam-Webster dictionary defines appreciation as "a feeling of being grateful for something." It's a simple act, saying "thank you" or "we're grateful for your support." I like to think that appreciation is the cousin of "being the good in the world." SAA is grateful for your support, because you help us do good in the world. Charity Navigator thinks so too! SAA is top rated with 4 stars again this year.

SAA is proud to be a member of the national nonprofit community. Like all nonprofits, SAA strives to fill gaps in information, advocacy, education, and support. Okay, I'll say it, at SAA we're do-gooders. It's a funny name, but we're used to funny names. It's a great reminder that in the beginning, SAA fought for "the disease with a funny name" to be recognized, supported, and talked about. And we like to talk about it! A lot.

Our staff is always searching for new ways to get the word out. Always thinking about the next program, the next campaign, the next project that will reach those in our spondyloarthritis community, and beyond. The frontline medical providers who see – and at times fail to promptly diagnose – those living with undiagnosed spondyloarthritis are one critical group we're focusing our energy on this year. We're also developing educational content for rheumatology fellows, and medical students, so that our future clinicians will have the most current and accurate spondyloarthritis information. (Please find more information on these programs on page 5 of this issue.) And we continue our efforts to raise spondyloarthritis awareness among the general public, moving the awareness and education needles with each social media post, each patient seminar, each video interview with an expert, each educational or awareness focused article or advocacy prompt, and with each passing year of our Global SpA Summit.

But we're not the only ones working to get the word out. You are our partners in raising awareness and educating your community. Every time you hold a fundraiser for SAA on Facebook or staff a health fair with our informative brochures, the word spreads just a little further. It does good. So, I'm grateful, I'm appreciative and I'm proud to be a do-gooder. I hope you are, too.

The support you give SAA and good deeds you do to help others living with spondyloarthritis help us fulfill our important nonprofit mission. And we shine brighter and do good, because of you.

~Cassie

Cassie Shafer
Chief Executive Officer

LETTERS TO THE EDITOR:

"The article [on SpA complications by Dr. Khan] was extremely helpful. I have had AS since age 14 and was diagnosed at 21. I turn 73 next week. Diagnosed HALB-27 positive and throughout my struggle with this disease, I have experienced countless health issues. In spite of these medical conditions, I know I am very fortunate and do not let them overtake my life. I thought I could manage on my own, until now. Dr. Kahn makes the connections that no other doctor has made in my lifetime. I anxiously await the next installment.

Back in the early 1980s, I was active in starting the first AS support group with Jane Bruckel. The lag time for a proper diagnosis was outrageous for females. Sadly, I didn't stay active or keep in contact with Jane or the group. Back then my family, profession, and the disease were all I could manage.

I am so proud of my beginnings in this group. I marvel at the organization's incredible progress. Thank you to everyone involved for its ultimate success. And thank you, Jane and Harry Bruckel, for your tireless dedication to this organization. Without you, Jane, it would have never become what it is today. Congratulations!"

Gratefully,

~ Mary Ann

Editor's Note: We received many touching letters in response to our last issue's article, "Opioid Restrictions Squeeze Many SpA Patients Out of Pain Relief." We're sharing a few, with our deep thanks, below.

"I thought your article on opioids was very well done. We need to speak up about chronic pain and the realities of living with it 24/7, for years, and how that affects our quality or non-quality of life. Since we can't put medical professionals and policy makers in our bodies for about 10 minutes, so they will understand what living with chronic pain is like, we must be able to advocate for ourselves in this way. Just to add a little more fun to what we have to deal with. Your article is empowering and shows the way, and who, to appeal to if our pain management is hindered and includes any kind of pain meds. I will bring this article up at our next support group meeting. Well done!"

- Tim

"I want to thank you for writing that brave article on pain in the last magazine. I take low-dose opioids as I'm not able to use NSAIDs anymore. I looked at the NPAC site you mentioned and was surprised and happy to find a group of people that are supporting people in pain who have the need for painkillers. It was very surprising (and comforting) to find that only 1%-8% of legitimate opioid users become addicted. I've been using them since 2006 and I say to people that question my use, 'If I were going to get addicted, I probably would have done it by now.' The pendulum analogy is excellent. Twenty years ago, they were handed out like M&Ms. Ten years ago, the attitude was guarded use. And nowadays, you're considered a junkie and doomed to rehab if you use them at all. I feel fortunate that my very thick medical dossier shows my controlled use over these 15 years. That lets my newer medical providers know that I can 'tickle the dragon' without getting hooked. In fact, having an extensive medical record with AS has helped me advocate for myself. But tragically, we Spondies seem to have to get a thick record before we're taken seriously. And if the record is filled with misdiagnoses, getting some traction for decent care is really difficult."

~ Ed W.

CONTENTS:

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
16430 Ventura Blvd., Suite 300
Encino, CA 91436

Please note that we reserve the right to edit for space and clarity.

LETTERS TO THE EDITOR: *(cont.)*

"Opioids are a very touchy subject. Many of us, like me, have lived life the best we can in spite of pain. I tell people who have been recently diagnosed with one of the spondyloarthritis diseases (and very nervous about their life) that they may have to trade some things, but a good life is theirs for the having.

We have seen some people in our support group change careers because the one they were working in was no longer feasible. A head chef was looking at an at-home computer job. A contractor was going back to school to get training in the insurance field. I could no longer run our large vending business and got training in fine arts so I could teach and sell my artworks. Some decide they must work part-time instead of full time.

For me, the daily pain I have dealt with for 25 years changed after year 20. I had a double back fusion. The surgery was a success in every way, except my overall pain levels increased. I believe my touchy nervous system said 'enough!' For several years prior I took one or two opioid pills a week, mostly on weekends associated with cleaning or gardening. But after this surgery I had chronic pain day in and day out. I finally had to give in and see a pain management doctor to come up with a game plan.

That plan includes Vicodin and Tramadol, a muscle relaxant and NSAIDs. But I also developed a comprehensive game plan that goes beyond pain medications so that I have the best life I can. I combine weekly massage, pool exercise 4-5 times a week, methotrexate, heat, cold, Voltaren gel, and several supplements… along with pain medications. If any of these are skipped or overlooked, I will have many long days of fatigue – unproductive days! – the type of fatigue that sends me to the couch or bed.

I've never had a loopy feeling from pain medications. I've never taken more than what is prescribed and consult with my pain management doctor every two months. His philosophy is that if pain medications allow you a life, then by all means, use them.

The atmosphere for chronic pain patients is scary. You are not supposed to save extra pain medications. But in this environment, it's hard not to! The amount I take is considered low, but I've had comments from pharmacists, comments from other doctors, and certainly from friends. I counter with, 'You do know I see a pain management doctor every two months? I consult with him and have come up with a plan that works!' I believe it is fear that causes them to question me. But it can feel quite disheartening and judgmental.

I know a couple of pain patients personally that have moved to states that allow marijuana use. It had gotten so hard for them to get opioids, they had to try something. They literally had to uproot their family to have their painful medical condition treated. We really should STOP grouping illegal drugs like heroin with legitimate pain treatments taken by people simply wanting to have a life. The data is strongly on our side, so to those trying to limit us, just look at the stats that apply to us using legally prescribed meds. It indeed is time to fight for the right to have our painful medical condition treated."

- Lynda K.

HASTENING SPONDYLOARTHRITIS DIAGNOSIS: FOCUS ON HEALTHCARE PROVIDERS

by Elin Aslanyan

One of our greatest frustrations at SAA is that despite all of the advances made in spondyloarthritis over the past few decades, consistent early diagnosis of this group of diseases has largely remained out of reach. Though real progress has been made in disease understanding, research, and expanding (and improving) treatment options – and while spondyloarthritis is receiving much more coverage in medical conferences and peer reviewed journals, and more attention from researchers – the average time it takes for a person to be diagnosed with spondyloarthritis is still about seven years.

That's seven years in which an undiagnosed person is living with symptoms they don't understand and don't know how to manage. Seven years of the disease doing its damage, uncontrolled and unchecked by treatment – damage that cannot be undone. It's unacceptable, and changing it is imperative.

SAA has been studying this issue for some time now and we believe that a key part of the solution is increasing awareness and knowledge of spondyloarthritis among first-line medical providers – the medical professionals our undiagnosed patients are likely to encounter early along the road to diagnosis.

We have been working hard on creating educational programs for health care providers, focused on recognizing spondyloarthritis in undiagnosed patients. We're excited to give our readers a sneak peek here!

Introducing SAA's Primary Care and Chiropractic Initiative: Accredited Continuing Education Delivered Online

Thanks to generous funding from a long-time, valued donor, SAA was able to conceptualize, develop, and will soon begin executing two interactive, highly engaging, accredited online learning modules. One is specifically designed for primary care providers – including PCPs, NPs, and PAs – and a second is designed for chiropractors. While these two learning activities have different audiences, and differ somewhat in their specific content, the main objective of both is to aid these medical professionals in the early recognition of axial spondyloarthritis (axSpA) symptoms. To ensure medical accuracy, as well as appropriateness for the target audiences, each activity was developed in close partnership with rheumatologists, as well as the medical providers who are the intended audience. We share a little about each activity below.

Demystifying AxSpA in Primary Care: Recognition, Diagnosis, and What Comes Next

This educational activity will aim to increase recognition and understanding of axial spondyloarthritis in this key population, specifically focusing on helping the learners identify key signs and symptoms, conduct an appropriate work-up, and know when to refer patients to rheumatology.

Spotting Axial Spondyloarthritis in Chiropractic Settings: Is AxSpA Behind Your Patient's Back Pain?

This is a unique, chiropractic-targeted educational activity, geared toward helping chiropractors appropriately suspect axial spondyloarthritis in their chronic back pain patients, and urge them to refer for further evaluation. It will also stress the danger of specific chiropractic modalities (high velocity "adjustment") for anyone with possible spinal fusion.

Both of these online learning activities have now been accredited, and will be launched in the coming months.

Reaching Future Physicians and Rheumatologists

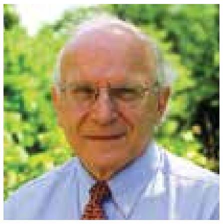
We can't neglect reaching future clinicians in our efforts to reduce the axSpA diagnostic delay. To this end, we are developing educational multimedia content specifically geared to two groups: medical students, and rheumatology fellows. All content will be created and presented by respected rheumatologists in the field of spondyloarthritis.

The course content for medical students will introduce axial spondyloarthritis to this population in three presentations: introduction to axSpA, physical exam and history taking for axSpA, and an overview of axSpA diagnosis.

The course content for rheumatology fellows will present an appropriately higher level, more complex instruction, while still providing a refresher of the basics. This series will also consist of three presentations: epidemiology and clinical features of axSpA, mimics of axSpA, and imaging in axSpA.

We look forward to sharing this series with you in the coming few months, and thank our corporate sponsor, UCB, for their financial support of this project.

SAA's COVID-19 AND SPONDYLOARTHRITIS SURVEY: TURNING YOUR VOICES INTO VITAL DATA



by James Rosenbaum, MD

For generations, patients have turned to their physicians for advice. But what if the doctor lacks enough information to provide the appropriate response? Most physicians like to offer answers that can be labeled "evidence-based." We as physicians have even devised ways to grade the quality of evidence, with the best source being a trial that is randomized, double-blind controlled, and adequate in size to provide a clear answer.

And then along came the COVID-19 pandemic. Suddenly the inboxes of rheumatologists were flooded with questions like: Will my disease make it more likely for me to contract COVID? If I do get COVID, will the infection be more severe? Do my medications affect whether I will get COVID? And if my medications do put me at increased risk, is it better to stop or delay them, or should I continue taking them even if they increase my risk of contracting a virus that can cause a potentially fatal infection?

In March 2020, as the pandemic's momentum was just starting to grow, the SAA made the decision to do what it could to fill the knowledge gap created by this novel virus. SAA partnered with Hedley Hamilton, who owns Any-3, a London-based survey design company, and has a personal interest in ankylosing spondylitis (AS). Together, Hedley, the SAA team and I created a major, ambitious survey to collect critical information on the intersection between COVID and spondyloarthritis, by going directly to the source: you, the members of the SpA community. Emails were sent to about 45,000 individuals in North America with SpA. Working with the Ankylosing Spondylitis International Federation (ASIF), we sent roughly an equal number of emails to individuals with SpA elsewhere in the world. Respondents were asked to complete the survey anonymously and provide answers to questions that aimed to capture the experiences of the SpA community over the course of the pandemic. The survey was translated into and administered in 19 languages.

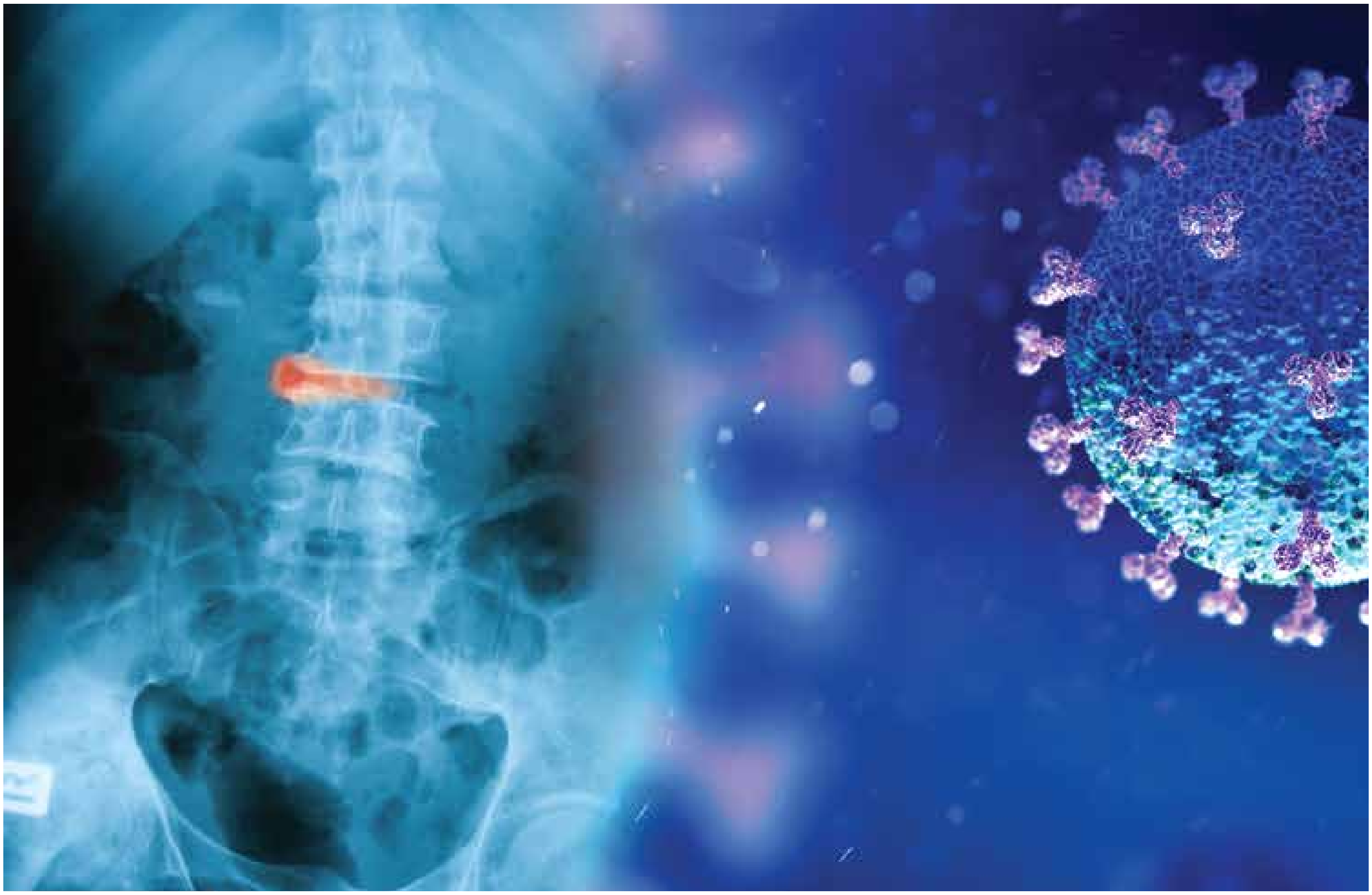
While our survey produced results that are very reassuring as far as overall COVID risk for our community, and while thousands responded to our survey, the precision of a study like this is limited. One problem is that those who respond to a survey might not be representative of the SpA community as a whole, which is a wide and varied group. For example, someone might be more motivated to participate in a survey about COVID if a relative had COVID and there was possible exposure. Another problem lies with inaccuracies that stem from misunderstanding one's own diagnosis. In one study, nearly half of respondents who thought they had lupus did not have lupus based on a review of medical records. A third issue is the risk of dying from COVID. Certainly, death is the most feared outcome from COVID. And needless to say, those who pass away from COVID cannot respond to a survey. Finally, there's the issue of association vs. causation. Let's say that we find that smokers are more likely to get COVID than non-smokers. Such a result does not necessarily mean that smoking makes one more susceptible to COVID. It could be that smokers drink more coffee or more whiskey than non-smokers, and it's the coffee or whiskey that makes you more susceptible, not the smoking. It could be that smokers are more likely to have low income and lower income people tend to live in densely populated areas where COVID can spread more rapidly. These confounders mean that epidemiologists always conclude that they have found an association, but they cannot conclude that it is an association that proves causation.

Even with these limitations in mind, our survey has provided vital information for patients and physicians, and led to the publication of numerous reports in peer-reviewed journals. We think our data show that SpA does not markedly increase the risk of developing COVID.[1,2] Along with that, we did not find that having the HLA-B27 gene affected the risk of getting COVID.[3] And we found that the medications commonly used to treat SpA, such as non-steroidal anti-inflammatory drugs (NSAIDs) or TNF inhibitors, do not affect the risk or severity of COVID. [1,2,4]

One of the "clever" devices we used in our survey was enrolling household members of our audience who did not have SpA. In this way, we could control for some of the exposure factors that are so critical in the risk to develop an infection. Another strategy we used was to ask respondents to submit answers several times. By including those who did not have COVID initially, and following up with them over the course of more than a year, we minimized the bias of only surveying subjects who were more likely to have been exposed to COVID.

We also found that HLA-B27 positive patients who responded to our survey tended to have lower disease activity scores as judged by the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI)[6] than patients who were HLA-B27 negative. This was a surprise finding which we interpreted as an existing healthcare bias in how back pain is viewed, and how SpA is diagnosed, based on the patient testing positive or negative for the HLA-B27 antigen.[5] In other words, someone who is HLA-B27 positive may be more likely to be diagnosed earlier in the course of their disease, before symptoms worsen, since testing for this genetic marker is a common diagnostic tool. On the other hand, someone with the same level of SpA disease activity and severity of symptoms who is HLA-B27 negative may not receive that diagnosis.

As an author of peer-reviewed reports based on these studies, I am grateful to Cassie Shafer, CEO of the SAA, and the SAA Board of Directors for authorizing and agreeing to fund the study. I am grateful to my co-authors, especially Hedley Hamilton, whose knowledge of web surveys was invaluable, and to Dongseok Choi,



who applied his statistical knowledge to interpret the results. Most of all, I am grateful to the patients, and their household members, whose time and effort provided information that is invaluable to others, at a time when so much was unknown. None of this would have been possible without your participation, and your trust in our work. A heartfelt thank you to each and every person who took part in this uniquely important survey.

Manuscripts published to date as a result of our COVID survey:

1. Rosenbaum JT, Weisman MH, Hamilton H, et al. The interplay between COVID-19 and spondyloarthritis or its treatment. ***Manuscript submitted.*** 2021.
2. Rosenbaum JT, Hamilton H, Choi D, Weisman MH, Reveille JD, Winthrop KL. Biologics, spondylitis and COVID-19. ***Ann Rheum Dis***. 2020;79(12):1663-1665.
3. Rosenbaum JT, Hamilton H, Weisman MH, Reveille JD, Winthrop KL, Choi D. The Effect of HLA-B27 on Susceptibility and Severity of COVID-19. ***J Rheumatol***. 2020.
4. Rosenbaum JT, Weisman MH, Shafer C, et al. Correspondence on 'Factors associated with COVID-19-related death in people with rheumatic diseases: results from the COVID-19 Global Rheumatology Alliance physician-reported registry.' ***Ann Rheum Dis.*** 2021.
5. Rosenbaum JT, Weisman MH, Hamilton H, et al. HLA-B27 is associated with reduced disease activity in axial spondyloarthritis. ***Sci Rep.*** 2021;11(1):12331.

6. ***The Bath Ankylosing Spondylitis Disease Activity Index (BASDAI)*** is an established self-administered measurement tool that allows a physician to determine the effectiveness of a current drug therapy by measuring severity of fatigue, spinal and peripheral joint pain, localized tenderness, and morning stiffness. Scores range from 0 (best) to 10 (worst); a score >4 indicates active disease.

Our thanks to AbbVie
for their financial support of this survey,
and to Novartis for their financial support
of our COVID-19 resources.

abbvie NOVARTIS

Our New Mug is Available Online!

https://spondylitis.org/get-involved/educational-products/

SAA VOLUNTEER HELGI OLAFSON GOES THE DISTANCE FOR SPA AWARENESS

by Sean Ewert and Helgi Olafson

Helgi Olafson was diagnosed at age 19 with ankylosing spondylitis (AS). His diagnosing doctor was supportive, gave him options, and assured him that his life wasn't over; it had only just begun. Helgi was determined to face what life had dealt him and turn it into something positive. He began his life's new journey, focusing on living an active lifestyle while maintaining a positive attitude, and never stopping.

Helgi is a spondyloarthritis warrior who is also a seasoned trail runner who competes at the highest levels of the sport. He uses the exposure he garners to support the causes he believes in. He is dedicating his current event, ***The Triple Crown of 200s***, to raise much-needed funds and awareness for SAA. The event will take him on a 2,858 mile journey via three endurance runs: Bigfoot 200, Tahoe 200, and Moab 240. This year, he is taking this already jaw-dropping feat to the next level by also running or cycling the distances between the three events.

Helgi's run to support SAA's mission and inspire others affected by SpA began on August 13 and will continue through October 12, 2021.

As an ultra-runner, Helgi likes to be one with the elements of nature. Through his own battle with AS, he has built the mental fortitude to put himself through intense athletic challenges, where the only way forward is through. In the 200-mile ultramarathon scene, he has become a figure of sorts, being very transparent about the struggles and victories he experiences before he even gets to the finish line. Helgi looks at every race as not only a journey, but also a battle.

Helgi and his team are using GPS tracking and adhering to a daily schedule. The team consists of two fulltime team members who both play a role in setting up crew access points every day and filming/photographing the challenges and triumphs that Helgi and the crew will face to keep the adventure going. Though there will be times when Helgi is solo, there will also be one or more pacers at any given time who will join him on many sections of the route. The route is mostly on trail.

Helgi's own words best sum up this amazing project:

"Having ankylosing spondylitis has really inspired me to take chances I may not have otherwise taken. It's almost as if this disease has somehow made me stronger within. It's the communities surrounding the things I believe in that have inspired me to strive to make a difference in the lives of current and especially future AS patients from around the world. Therefore, I hold my relationship with the Spondylitis Association of America in such high regard."

SAA is so grateful to have Helgi's support. If you would like to join us and help cheer him to the finish line, please scan the QR code to learn more about, and support, this inspiring event.

CORPORATE SPONSORSHIP

The corporate membership program provides a way for corporations to positively impact the lives of those affected by spondyloarthritis by contributing to SAA's general operating budget. SAA also receives additional corporate support for special – and costly – programs such as SAA's patient education seminars.

PLATINUM SPONSORS

abbvie

ucb Inspired by **patients.**
Driven by **science.**

NOVARTIS

GOLD SPONSORS

Pfizer

SILVER SPONSORS

AMGEN®

BRONZE SPONSORS

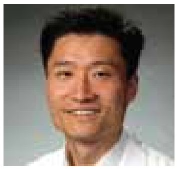
Lilly

Boehringer
Ingelheim

OTHER CORPORATE MEMBERS

janssen
PHARMACEUTICAL COMPANIES
OF Johnson & Johnson

COMPLICATIONS AND COMORBIDITIES IN LONG-STANDING SPONDYLOARTHRITIS:



PART 2

An interview with **Steve Lee, DO, FACR**, Rheumatologist and Member of SAA's Medical and Scientific Advisory Board

We're continuing our exploration of the possible impacts of long-standing spondyloarthritis (SpA) that we began with Dr. Muhammad Asim Khan in our Summer 2021 issue of ***Spondylitis Plus***. Many thanks to Dr. Steve Lee for contributing his expertise to this important topic.

Spondylitis Plus: Can we discuss the risks of osteoporosis and fractures in long standing SpA? Who is at heightened risk? Why? And what screenings and preventative measures are recommended?

Dr. Steve Lee: Several factors can predispose one to osteoporosis and complications of fractures. First, many patients limit their physical activity due to pain and mobility challenges. Certainly exercise, and in particular moderate weight bearing activity, helps keep our bones strong and muscles firm to support posture and function. Those who aren't incorporating activity into their routines are missing out on this protective measure. Next, SpA patients typically form extra bone in the spine, pelvis and other sites, and chronic inflammation can lead to abnormal architecture and osteoporosis. Finally, when one needs intubation for surgery or severe illness, a neck that has limited flexibility can suffer the rare surgical complication of neck fracture.

Those with low vitamin D, smokers, and those with poor nutrition including inadequate calcium are at greater risk for osteoporosis. Women generally have greater risk as well. Screening for women generally starts at age 65, or earlier if risk factors like SpA, family history, smoking, or others are present. Men generally start later but guidelines are variable. All of us lose some bone gradually as we age. Most SpA patients are not on chronic steroids, but this can also be a risk.

Spondylitis Plus: What are the long-term risks and implications of recurring iritis/uveitis? What is recommended for a patient experiencing regular bouts of iritis?

Dr. Steve Lee: Recurring inflammation in the eyes can ultimately lead to impaired vision and vision loss. Topical steroids can increase the risk for infection and can accelerate cataracts, which also impair vision. Ongoing monitoring by your team of ophthalmology and rheumatology specialists can help calm the inflammation. In particular, the TNF inhibitors, aside from etanercept [Enbrel], seem to be quite effective in the treatment and prevention of iritis/uveitis.

Spondylitis Plus: How common is spinal stenosis in long standing spondyloarthritis? And does SpA cause, or at least contribute to it? If so, how?

Dr. Steve Lee: Spinal stenosis is the result of degeneration and extra bone growth in the spine that can lead to narrowing of the spinal column. This can cause chronic low back pain that can radiate and tends to improve when one leans forward. Though the symptoms of spinal stenosis are different from those of SpA and bone growth in SpA tends to be marginal (less bulky than in spinal stenosis, and with less encroachment into the spinal canal itself), spinal stenosis can accelerate with spondyloarthritis, especially as we age.

Spondylitis Plus: What are some indicators that a consideration of surgery is warranted?

Dr. Steve Lee: Thankfully, fewer SpA patients are requiring posture correcting surgery of the spine and hips, largely due to the potent and effective medications that have been developed over the past 23 years. But if enough damage occurs over time to limit function or range of motion in the neck or hips in particular, surgery – though complex – can be helpful. Hip replacement is sometimes used if cartilage is lost, and various spinal column straightening procedures may be performed, but require a highly skilled and experienced surgeon.

Spondylitis Plus: Are those with SpA more likely to need joint replacement (such as the hip or knee) than the general population? If so, do we know why? What mechanisms in SpA may be contributing factors?

Dr. Steve Lee: The chronic inflammation that occurs in SpA can accelerate cartilage loss, in particular in the hips and axial skeleton (spine and pelvis). Some with peripheral SpA may require knee replacement as well. Most biologics need to be held for some time prior to planned surgeries. Complications like infections, abnormal bone growth (heterotopic ossification) and challenging rehabilitation can complicate surgical procedures.

Spondylitis Plus: Pain, fatigue, and brain fog. There aren't great answers for these. What do you tell patients who are suffering from uncontrolled pain, fatigue, and brain fog?

Dr. Steve Lee: Though no one treatment works for all patients, there are numerous options for even stubborn SpA inflammation. Many with chronic inflammation report significant fatigue and even cognitive symptoms like brain fog. The prevention and control of inflammation and patterns of pain that can become chronic are key to managing these symptoms. A multi-disciplinary approach led by teams of physicians may be needed. Rheumatologists, physiatrists, orthopedic and spine surgeons, and mental health clinicians can all help us in our daily function. Pain specialists can incorporate options like acupuncture, botanicals, mindfulness, and analgesic strategies to help patients cope. Certainly, optimizing restful sleep and healthy nutrition may also be helpful.

Spondylitis Plus: Patients have heard that aneurysms may be brought on as part of the comorbidities of spondyloarthritis. Can you speak to this concern?

Dr. Steve Lee: Thankfully, aneurysms are rare and not likely directly related to SpA, but cardiac complications like a dilated aorta have been documented. Most physicians will periodically listen to your heart and abdominal aorta, and check for symptoms of heart problems.

Spondylitis Plus: What should those living with long-term SpA know that may be comforting? How do you reassure patients?

Dr. Steve Lee: There have been many exciting advances in the past couple of decades in SpA research. There has been a major push for earlier diagnosis, looking at genes that make a person more susceptible to SpA, and continuing to explore gender differences. Researchers are also studying mechanisms of disease pathogenesis [development], in particular the microbiome. From this knowledge, new areas of targeted therapies that block inflammation-causing parts of our immune system are being developed and can now be used in clinics to get symptoms under excellent control in many instances. Medications are becoming more accessible as well, as competition increases in the areas of biosimilars and upcoming oral formulations of anti-inflammatory medications. So there is reason to believe our understanding and treatment of SpA will continue to advance significantly into the future!

YOUR STORIES:
I WAS THE FAT KID

by Rick Philips

There comes a time in every person's life when they adopt what they come to believe about themselves. At some point in my childhood, I had been told enough that I was the fat kid that I adopted the narrative. But this story is not about childhood trauma or the dangers of being teased. It is true that at some point, I decided I was the fat kid. But if the story had remained there, I would not be telling it, and you might never have any interest in reading it.

First, I was diagnosed with diabetes. In 1973, I attended the Philmont Boy Scout experience in New Mexico. It was amazing. For 10 days, I backpacked about 80 miles over and around mountains. Carrying at times a 60-pound pack, I felt I had grown up a great deal. I loved it so much that I wanted to return the following year in 1974 for two experiences. I intended to backpack for around 25 days and total about 150 miles. I knew it would be tough. So, when I got back in 1973, I started training immediately.

I also started feeling something else. For the first time in my life, I began to have an aching back. I had good reason. My back started hurting just as I was increasing the load in my training pack. At one point, I was carrying around 80 pounds of bricks and other debris to mimic a full pack on the trail. I treated my back with ice and lying flat on a wood floor.

I was no longer the fat kid. I was losing weight, and my muscles were getting tighter. It did not matter what I ate; the pounds would fall off. It made sense. I was 16, was very active at this point, and of course, the testosterone was raging. I was growing into a man. Except more was going on.

In June 1974, I was diagnosed with type 1 diabetes. By the time I was diagnosed, I had lost around 25 pounds, and I was exhausted. (As a side note, I was on vacation with my family at Walt Disney World at the time. No offense to Disney, but it proves that Disney World is not always the happiest place on Earth.) I was released from the hospital on my 17th birthday. Once I started insulin, I almost instantly gained 20 pounds back. I also got to complete my 25-day adventure that summer.

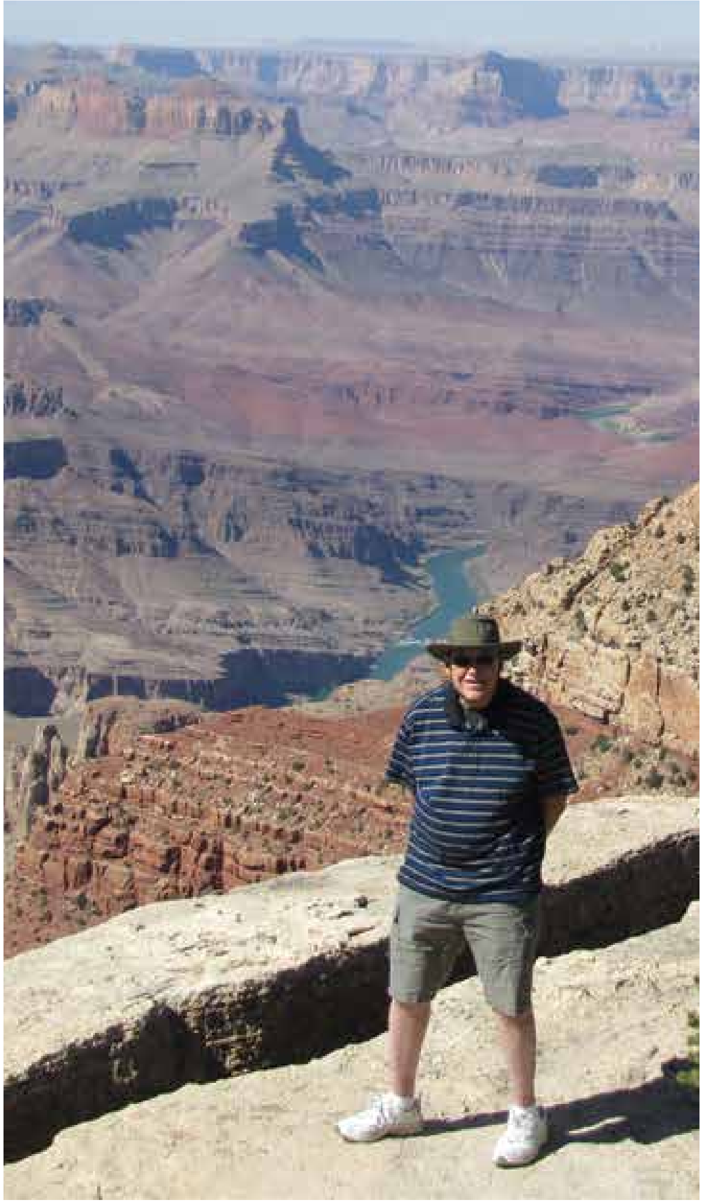
In my second year at Philmont, my back ached with terrible pain. I lay down each night on the ground inside my sleeping bag and felt some relief. Each morning I awoke stiff, and I took several minutes to stretch and bend. Each day was difficult, and it got worse as I went on. But I made it through. I carried around my entire life in a backpack with a frame and figured an aching back made sense.

I also gained weight over that summer. The reason I gained weight so fast was simple. It was insulin. Insulin is a hormone, and its purpose is to metabolize and regulate glucose. Without insulin, glucose is not metabolized, and cells in the body are starved for energy. In my case, my body had been starved at the very same time it was growing. It was like a two-part punch. My body was demanding more glucose during a time when I could not process glucose. In June of 1974, I weighed 185 pounds, and by the time I graduated from high school in May 1975, I weighed 212 pounds.

It is essential to stop here for a minute and explain that type 1 diabetes is an autoimmune disease. In my case, diabetes at age 17 offered a preview of the immune system dysregulation I would experience later on due to ankylosing spondylitis (AS).

As I got older, I continued to gain weight. When I finished college, I was around 225 pounds. I thought of myself as slightly overweight, but not so much so that I couldn't stabilize if I made an effort. I might have been able to stabilize it, but I did not.

Instead, I began my career in a job that required me to sit most of the day. I started to gain weight in large chunks. I did not exercise, so my blood sugar started to rise. The more it rose, the more insulin I took, and the more weight I gained. If it sounds like a terrible cycle, that's because it was. As I gained weight, my joints ached even more. As early as 1985, I could feel once again that



awful pain in my back. I attributed it to weight gain, and to some extent, it must have been.

Finally, in 2000, I reached out to my endocrinologist about the pain I was experiencing. He referred me to a rheumatologist, who diagnosed me with rheumatoid arthritis. I was relieved. Finally, I had an answer for the awful joint and back pain that was making my life so difficult. I started taking Remicade and felt almost instant relief.

By the time I was 40, I weighed 325 pounds. I learned that I needed heart surgery to correct an AV fistula (an abnormal connection between an artery and a vein). It was a congenital anomaly I had since birth, but my weight likely exacerbated it. The larger I got, the harder my heart was working, and the more this minor issue became a big deal.

The doctor who did the surgery was reluctant because of my weight. He said, "Look, you are beyond what I would ever operate on. I have upper limits for heart surgery. I will agree to do it, but if you show up here weighing more than you do now, I will not." I made it under the surgeon's weight limit, and had the surgery.

In 2008, I was forced out of my job. I won't elaborate but suffice it to say that it was a good decision by my employer. By 2007, Rituxan was no longer helping me as much as I needed, and the new medications my doctors prescribed were not working at all. In rapid succession, I tried and failed four more biologic medications between 2008 and 2013.

I also returned to college. See, I was no longer going to work, so that's what I did to feel productive and like I still mattered. Heck yes, let's get a doctorate. I love going to school and everything about it. It took five years, but I enjoyed every minute of the work, interactions, and learning.

However, by the time I graduated, I weighed 370 pounds. The truth was that even walking out to get the mail was drudgery. I worried that I might not make it up the little hill of my driveway. When my surgeon replaced my hip in 2013, he ended my penchant for bike riding. He said that if I wanted to ride a bicycle, I would need to ride a three-wheel adult tricycle. If you have ever ridden a three-wheel contraption, you know it's nothing like a bicycle. It turns unevenly, you can't go fast, and getting up a hill is less than fun. I was not fond of it.

In early 2014 I finished my dissertation and got ready for my annual visit with my cardiologist. I knew what I would hear. "Lose weight" was our constant topic of discussion. I could almost say it before she started. But in addition to her talk about losing weight, I had a concern. It seemed I could barely breathe even with minor exertion, and worse still, I could feel the thoracic bone in my chest shift and pop when I moved. It was uncomfortable. She referred me to a rather abrupt and unkind pulmonologist for a review.

It turned out I had a broken sternum, and I was sent back to the thoracic surgeon. My return visit was not great. He confirmed that yes, my thoracic bone had broken. All the glue and wires he used to patch it back together in 2006 were no longer holding. Then he put me on the spot. He said he could not repair my chest unless I lost at least 100 pounds.

I felt like I had just been told to climb Mt. Everest. At first, I got angry. Incredibly angry. Did he not understand the pain I was feeling? On reflection, I'm sure that he did. Fortunately, in the next few days, I had a regularly scheduled appointment with my endocrinologist. I discussed various options with him, including bariatric surgery, and he said his office offered a highly restricted food plan under the control of an endocrinologist.

My goal was to lose at least 100 pounds and to do it as quickly as possible. I gave myself one year, but I wanted it to be sooner. My diet consisted of either a solid energy bar or some difficult-to-drink shakes. My total calorie consumption was no more than 1,200 calories per day.

I started to exercise more, too. I began to ride my three-wheel adult tricycle (something my hip surgeon insisted on) more often. I worked hard to keep to my diet.

After 10 months, I returned to my thoracic surgeon's office, having lost 90 pounds. He agreed to do the surgery. As I was recovering from the thoracic surgery, I was alarmed to find that I had gained 15 pounds. I had come so far, and I did not want to give up my progress. That was when I began Weight Watchers (now WW). Since starting in 2015, I have lost an additional 70 pounds. It has been a long, arduous road—with no straight lines.

This is where I must stop the story again to explain something. I have terrific support at home. I would never have been able to do this alone. My wife (we have been married for 44 years) also joined WW, and we do it together. Sheryl regained her lifetime WW membership status and has kept it. She is a great inspiration for me. But inspiration or not, I would not have lost a single pound without her support.

In 2015, one year after the thoracic surgery, I was diagnosed with AS. My back had always hurt, but the pain in my surgical hip had grown so intense that I could barely tolerate it. I went to see my orthopedic surgeon. "No, it's not your hip," he said. "It's your spine." That year I had a lumbar laminectomy, and I started to feel a little better. During that surgery, the doctor saw the ravages of AS, and thus I gained my third chronic disease diagnosis.

In 2020, I had spinal surgery to correct severe kyphosis. I am still in recovery from that surgery. Looking back, I can remember my mother telling me to stand up straight as a teenager. By the time I had the kyphosis surgery, I was leaning forward so far that I was in danger of falling with every step. No doubt, the early signs of AS were present in 1973 as I was walking around with those bricks in my backpack. But who knew?

Today people often tell me that I look great. I agree. But there are two things I know. First, it has taken six years to lose as much weight as I have, and second, I will constantly be losing weight, throughout my life. I doubt there will ever be an end, or a "good enough." After all, no matter how much I lose, I will always be that fat kid.

SCIENCE & SYMPATHY:
A DIFFERENT APPROACH TO TALKING ABOUT PAIN

by Jason Blackwell

Stabbing. Debilitating. Sickening. Cruel. A picture may be worth a thousand words, but when it comes to pain, there's no single image or word that can accurately, and more importantly, empathetically illustrate how it feels. So, how can pain be discussed via a lens that is focused by both science and humanity? And why are conversations about pain often difficult to raise, and inclined to trigger anxiety? During Pain Awareness Month, SAA and other advocates try to unravel the multiple layers surrounding the causes of pain and its corresponding stigma, and create a safe space for engaging in conversations.

Chronic pain has physical, mental, and economic costs. According to research and studies published by researchers and the World Health Organization, chronic pain ranks as one of the most common reasons why adults seek medical care. Chronic pain also has been linked to restrictions in mobility and daily activities, dependence on opioids, anxiety and depression, and poor perceived health or reduced quality of life.

Consider some members of SAA's very own spondyloarthritis (SpA) community, for which uncontrolled pain remains a serious complication. While some of our members have been able to manage their symptoms and pain through traditional SpA treatment plans such as NSAIDs, biologic medications, exercise, and physical therapy, others continue to suffer from chronic pain. Science points us to multiple factors that can impact how the body responds to pain, including psychological and behavioral variables, centralization of pain, and even changes in mood.

But knowing the reasons why pain persists may only feel like a moral victory. For those who live with this chronic pain, raising awareness to boost visibility and advocacy efforts may provide relief – at least on a mental health level.

Fear of judgement, of not being believed; having one's pain minimized or dismissed; being labeled a complainer or faker; receiving criticism; getting accused of being a drug-seeker – these can all drive someone living with chronic pain underground to suffer alone in silence. Validation and understanding can spark an honest conversation. At SAA, our goal is to provide the information that empowers individuals living with spondyloarthritis and chronic pain to make informed decisions about their health. We create a safe space for conversations that are rooted in science and free from judgement. As a national health observance during September, Pain Awareness Month has been an opportunity to raise awareness of how pain affects individuals, families, communities, and the nation at large, and to support a national response to address pain.

Spondyloarthritis has been referred to as an invisible illness. The path to diagnosis is often arduous and long. But even after receiving a diagnosis, the journey is still only beginning. As a lifelong illness, there is not a finish line. Save your energy. You're not lazy. You're not invisible. And while chronic pain may continue to be a hurdle for some of you within our community, you are not alone.

Meet the Support Group Leader:
MIKE SUPANCICH

by Rachel Zaimont

Mike Supancich was a medical school student in 1966, working his way through grueling, 18-hour days, when he read an entry in a textbook that changed his life.

In truth, his life had changed long before he first read the words "ankylosing spondylitis" in that book. As a junior in high school, the avid surfer began suffering from back pain that hindered his ability to chase waves off the San Diego coast. At first he thought he'd injured himself and that the pain would subside over time, but his doctor ran tests that pointed toward inflammatory arthritis. As if that wasn't tough enough for the teenaged Mike, he also had to find a new group of friends – giving up surfing turned his lifestyle and social structure upside-down.

College was an even more challenging time. "I kept flaring up," he recalls. "I'd feel fine for a while, and then I'd feel like a locomotive hit me – major fatigue, stiffness, and pain. I was pre-med and had to drop units, and was very unhappy."

His doctor prescribed an unusual treatment: radiation to the lower back. Although this treatment isn't offered anymore due to safety concerns, it "turned off" his pain and allowed him to plow through the rest of his courses to finish undergrad.

At Northwestern University Medical School, he came across that fateful page devoted to AS in a textbook. "I read the description and I knew immediately: That's what I have," he recalls. Mike's self-diagnosis was confirmed by a rheumatologist a decade later.

Mike practiced ophthalmology for 25 years. He enjoyed a career as a pediatric ophthalmologist until a herniated disc landed him in surgery. Immediately, his AS symptoms returned. NSAIDs and prednisone helped, but he could no longer keep up with the children he treated, so he gave up pediatric ophthalmology and began treating adults. "It became very difficult in the last few years of my practice because my spinal stenosis was severe," he says. "At noon, I'd lie down on my office floor for an hour so I could work the afternoon."

If there's a silver lining to Mike's familiarity with spondyloarthritis (SpA), it's this: He was able to help diagnose dozens of patients over the years who came to his practice with iritis.

A sorely needed back surgery in 1996 forced Mike to retire. It's hard for him to say which was more painful – his AS or selling his practice. But a few years later, a glimmer of hope appeared.

Mike's rheumatologist wrote him a prescription for Enbrel just as studies were beginning for patients with AS. Within a few weeks, his symptoms improved drastically. He contacted SAA and founded the San Diego spondyloarthritis support group in 2003. Fifty people came to the first meeting, where Michael Weisman, MD, FACP, a member of SAA's Medical and Scientific Advisory Board, presented. Tim Tompkins, an early member of the group, stepped up as co-leader along with Mike. The pair run the support group together to this day.

"I've found support group leadership to be really rewarding. I've met a lot of great people. And I think we've done some good, so I feel positive," Mike says. He brought his passion for the support group program to SAA's Board of Directors in 2005, serving as Board Chair from 2008 to 2010.

Although AS forced him to retire from surfing and medicine, Mike has devoted his time to a wealth of interests throughout the years. He got his real estate license. He pursued his lifelong passion for exotic cars, competing in time trials with modified Porsches (although racing around the track at speeds reaching 165 miles per hour took its toll on his neck and shoulders, so he had to give that up, too). "The thing I liked about racing is, you're totally focused. You're not thinking about anything else in your life," he recalls. That heightened focus is also what he enjoyed about performing eye surgery, which he describes as "a ballet requiring extreme concentration."

Now Mike applies that concentration to photography – whether it's sportscars, animals, landscapes, or his large family.

Flexibility and mental resilience are the keys to living well with SpA, he believes. "Because of the disease, you have to be ready to alter your plans mid-stream. You have to accept when you can't do one thing, and move onto the next."

Editor's Note: This is the first installment of a new column, in which we'll spotlight one of SAA's creative, dedicated, kind, and welcoming support group leaders in every issue. To find a support group near you, visit **spondylitis.org/support-groups** or email **SG@spondylitis.org**.

SUPPORT GROUP LEADER CONFERENCE BRINGS SAA VOLUNTEERS TOGETHER – VIRTUALLY!

by Rachel Zaimont

"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has," the anthropologist Margaret Mead once said. At SAA, we believe that by providing uniquely safe, understanding, and judgment-free spaces for the spondyloarthritis (SpA) community, our volunteer support group leaders are doing exactly that.

SAA support group leaders from across the country came together online on July 17th for our 2021 Support Group Leader Training Conference, a virtual day of presentations, group learning, networking, and connection. During a program packed with educational sessions and social activities, support group leaders had the chance to meet and share experiences with one another, and gain advice and tips to bring back to their groups.

Conference attendees were treated to presentations including, "Facilitation and Inclusivity Best Practices for Your Support Group," "Marketing, Outreach and Recruitment for Your Support Group," and "How to Incorporate and Keep Zoom Engaging for Your Support Group," the last presented by SAA volunteer support group leader Roz Tolliver (Merced, CA).

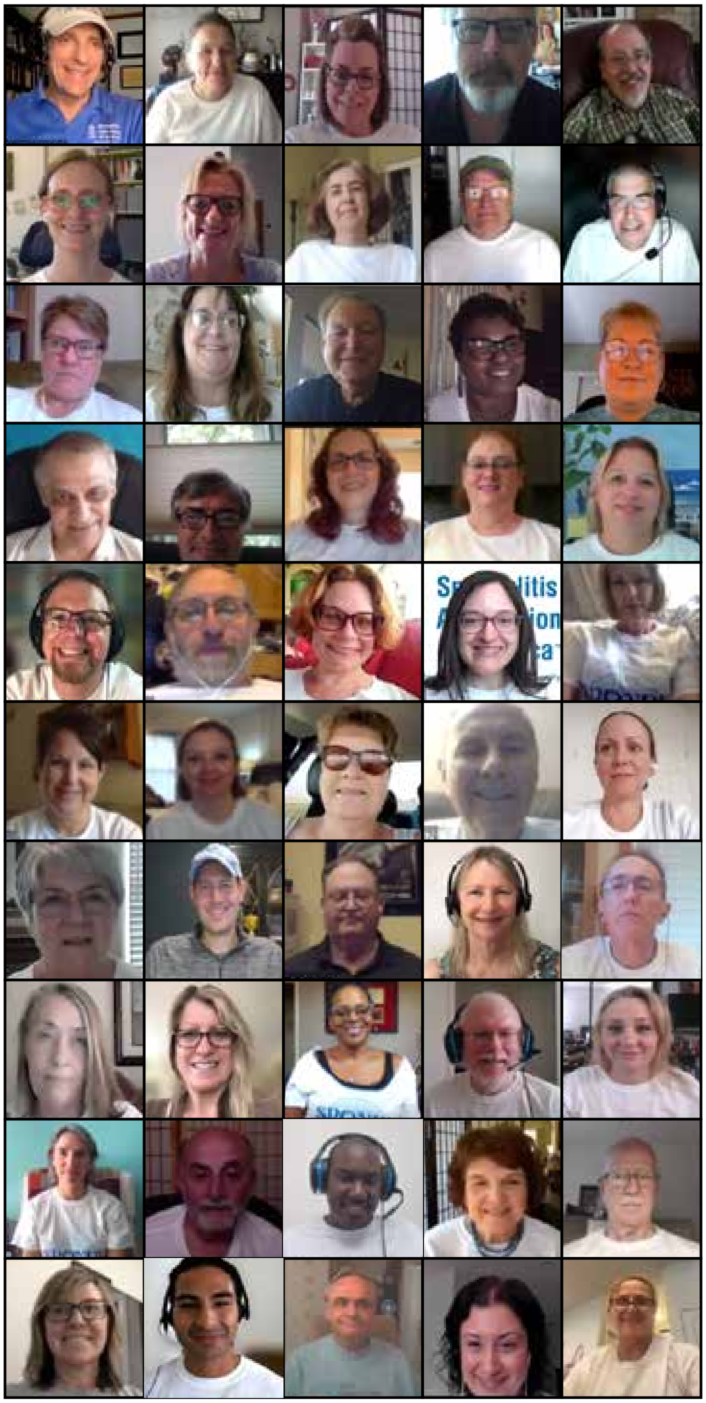
Participants found deep meaning and helpful advice in an afternoon webinar presented by Erin Baurle, PsyD, on "Self-Care for Support Group Leaders, Plus Crisis Management Tips." Rounding out the day, group leaders enjoyed an exercise session led by personal trainer, and fellow SpA warrior, Alex Levine, a fun and entertaining virtual scavenger hunt, SAA research and advocacy updates, and more.

The virtual conference was truly an event created by support group leaders, for support group leaders. A dynamic and involved volunteer planning committee shaped the content of the day in partnership with SAA staff. Committee members included Stephanie Phippen (Denver, CO), Jeanne Drennan and Liz Maines (Albuquerque / Santa Fe, NM), Iain McDonald (The Woodlands, TX), Howard Tevelson (Oakland, CA), Jessica Thomas (Chicago, IL), Roz Tolliver, Sandra Voss (New York City, NY), and Heidi Waltz (Piedmont Triad, NC).

"SAA volunteers always go above and beyond for our spondyloarthritis community," said SAA's CEO Cassie Shafer. "It takes special people with heart and passion to make sure those living with spondyloarthritis are seen and heard. Please know how grateful we are at SAA to call you part of our trusted family."

In his opening toast for the conference (as participants lifted their SAA mugs, received as part of a "goodie bag" before the event), Howard Tevelson thanked the SAA staff and planning committee for organizing the gathering. "We could not ask for a greater group of folks to work with and connect with," he said. "But most of all, this toast is for all of you who have given your time and energy to ensure that the people who come to our support groups know that there are others just like them."

We'd like to thank abbvie and NOVARTIS for supporting this program through educational grants, and everyone who makes our unique support group program possible – most of all our dedicated support group leaders, and the attendees who bring kindness, camaraderie, substantive conversations, and understanding to our meetings.



Would you like to join a support group? Locate a group that meets near you, or one that meets virtually, on our website, at **spondylitis.org/support-groups**.

You're Not Alone!

Find all of our support groups at
Spondylitis.org/Groups

More ways to connect at
Spondylitis.org/Community

Want to Speak with Someone at SAA?

Call us Toll Free* at
(800) 777-8189
and speak with a real live human being Monday through Friday!

*Toll Free available in U.S. only. International members can call us at **(818) 892-1616**.

Connect with Others Living with Spondylitis!

There are SAA-Sponsored Spondylitis Educational Support Groups in over 30 states throughout the U.S.

Is There One Near You?

This issue of
SpondylitisPLUS
is supported by
an education grant from
abbvie

The Spondylitis Association of America is solely responsible for the content of this news magazine.

Spondylitis Association of America™

16430 Ventura Blvd., Ste. 300
Encino, CA 91436
Phone 818.892.1616
spondylitis.org

Serving the Spondyloarthritis Community

COMBINED FEDERAL CAMPAIGN

SAA participates in the **Combined Federal Campaign** – the largest and most successful annual workplace charity campaign. Simply enter CFC code **#89466** on your pledge card during your agency's fund drive, or contact your Human Resources Department or the Office of Personnel Management (**www.opm.gov**).

Please contact us if you have given anonymously through CFC so you can continue to receive SAA member benefits. Email **hhart@spondylitis.org** or call **800-777-8189 x226**.