

SPONDYLITIS PLUS

Fall 2015

Central Sensitization
And Its Role In Chronic Pain

Research Presented At EULAR 2015:
Reporting From Rome

Medical Marijuana -
The Changing Landscape



**Spondylitis
Association
of America**

**SPONDYLITIS ASSOCIATION
OF AMERICA**

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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.*

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SPONDYLITISPLUS

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medications or products for spondylitis,
and always advises that you seek the
counsel of a physician before initiating
any treatment for spondylitis.*

ON POINT



Dear Readers,

At SAA, it is our mission to support research in axial spondyloarthritis, sponsor educational programs, advocate for improved treatments and access to those treatments, and also serve as a clearing house for putting people in touch with people. Yet, there is another issue that must be addressed — chronic pain and its management. Every day we hear from those who suffer with chronic pain, often without adequate recognition or relief. With your help, over the course of the coming months, SAA will explore pain from the scientific to the emotional and everything in between. To do this, we need to hear from you — your challenges, your stories and your successes.

In this issue of *Spondylitis Plus*, we sought to begin the “pain” discussion by inviting Dr. David Yu to write about pain from a scientific perspective. His article, “Central Sensitization and its Role in Chronic Pain,” can be found on page 10.

Each year, \$100 billion is spent on pain care in the US. Yet in spite of this, it is reported that 19% of Americans experience persistent pain, with an estimated annual cost of \$60 billion in lost productivity.

The good news is that in spite of the meager funding for pain research there are some highly dedicated people in the field making a difference. This can be demonstrated by the growth in the number of pain medicine publications and journals, pain medicine associations, passage of pain medicine legislation for the military and Veterans Affairs, and most recently, congressional activity to pass the National Pain Care Policy Act of 2009.

Significant advances are also evident in pain research, diagnosis, and therapy, including new techniques such as neurophysiologic testing, central nervous system imaging and diagnostics, and discoveries at the molecular and genetic levels of pain.

As the debate on the future of pain medicine unfolds, stakeholders at all levels are taking note of the exciting potential for an optimal system of pain care delivery. However, more delays in advancing the cause of pain medicine will place the United States even further behind other countries, such as Australia and China - which have already recognized pain medicine as a medical specialty - and the European Union and Canada - which are considering such a development. Therefore, in the interests of individual patients and the public at large, it is time to consolidate disparate interests in the pursuit of optimal pain treatment.

It has been suggested that this goal can best be accomplished through the establishment of pain medicine as an American Board of Specialties recognized primary medical specialty, the development of dedicated Accreditation Council of Graduate Medical Education-accredited residency programs in pain medicine, and support for comprehensive, integrated pain care services.

Let us continue the pain discussion; please write to us – it is imperative that we hear your voice and your stories.

Laurie M. Savage
Executive Director

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“Wow! Just read the latest issue of Spondylitis Plus (Summer 2015). Interesting that poop may be the source of answers to understanding ankylosing spondylitis. Whodathunk!”

~ Jimmy

Editor's Note: We got quite a response to what we've been affectionately calling “the poop story” here in the office! Glad you found it interesting, Jimmy. We did as well.

“Thank you! It [the webinar on Juvenile Spondyloarthritis hosted in June] was incredibly informative in understanding my own disease even though I am not a parent (although my mom watched with me!) I would love to attend more of these throughout the year. Thank you for the great promotion of S.W.I.F.T. I hope others can benefit from it as much as I have...”

~Webinar attendee

Editor's Note: The JSa webinar referenced above was held on June 13th. A recording of the program is available on SAA's YouTube channel, youtube.com/SPONDYLITISdotORG.

“I would love for there to be an educational seminar near the Bay Area or Sacramento area! There seems to be a lot in Southern California, and I can't wait until they have one in Northern California.”

~ Natalie

Editor's Note: As it happens SAA will be hosting an educational seminar in San Francisco on November 7th 2015! Check back soon for more information on this upcoming event.

“Thank you for all the support you provide. When I have questions about my condition, I go directly to your website and find the answer. I love the message boards. It's

comforting to hear from others who share the challenge of this disease.”

~Theresa

Editor's Note: Thank you, Theresa, for the kind words! We hope you find our new website even more useful and user friendly.



LETTERS TO THE EDITOR

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

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

When In Rome

Research Presented At EULAR 2015

The European League Against Rheumatism (EULAR) celebrated its 16th annual meeting in June in Roma, The Eternal City, much to attendees' delight. As EULAR celebrated its 16th by hosting 120 countries, we enjoyed the welcome of the city, and the kindness and open smiles of our hosts.

The unique quality of EULAR encompasses not only its mission to spark scientific and clinical progress in the broad field of rheumatic and musculoskeletal diseases, but also from its debut the recognition and value of "patient power." This year also featured a joint congress with the Pediatric Rheumatology European Society, which hosted an extended program in pediatric rheumatology. This year a EULAR record of more than 4,300 abstracts were submitted, with over 82% being accepted. Thus this short report will only cover a modicum of these.

One of the overriding themes of the meeting, which hosted more than 14,000 attendees, was the management of comorbidities associated with chronic inflammatory rheumatic diseases, including axial spondyloarthritis (AxSpA). The objective of EULAR was to see whether a standardization and homogenization amongst health professionals in this area could be achieved. Still consensus is lacking.

Below are brief descriptions of several abstract meetings at EULAR.

"Treatment in RA and SpA during pregnancy: Present and future."

Speaker: Monika Ostensen (Norway)

Over these past 15 years, effective new therapies in rheumatic diseases have not only vastly improved the lives of many, but also created a more complex therapy decision making

environment. This is doubly true for female patients considering pregnancy.

Previously, it has been substantiated in research that both Methotrexate and Cyclophosphamide therapy should be halted before a planned pregnancy. Little is known regarding the DMARD Leflunomide and so therefore discontinuation continues to be recommended prior to conception. Professor Ostensen cautions that since little data is available regarding pregnancy, exposure to, and fetal side effects for biologic medications, a decision between the doctor and patient should be based on severity of maternal disease and considered when no other safe options are available. The bottom line regarding this discussion is that although previous data includes a limited number of pregnancies, they continue to confirm previous reports that show no increased risk of major malformations or other harmful consequences in patients exposed to biologic therapy around conception.

"The effect of TNF inhibition on radiographic progression in ankylosing spondylitis: An observational cohort study of 384 patients."

Abstract by: Walter Maksymowych (Canada)

According to a new study, smoking is a major factor that prevents patients on TNF-I biologics from achieving sustained remission. The research conducted in Canada with more than 300 patients also found that in younger patients with shorter disease that if their C-Reactive Protein (CRP) levels could be normalized soon after treatment, that these patients were then much more likely to experience sustained remission. The study concluded in multivariate analysis involving 323 patients (of whom 75% were male) that age, smoking status, and normalized CRP were the strongest predictors of sustained remission measured by MRI. The study researcher commented that it would seem that smoking in AS is related to more severe disease in ways that are not yet understood.

“New optical in vivo imaging of the Alarmin s100a9 in an experimental autoimmune model of rheumatoid arthritis.”

Abstract by: Stefanie Zenker (Germany)

A new way of measuring inflammation that is non invasive has been tested in RA patients in Germany. An optical imaging system called a Fluorescent Tracer has been shown to yield good imaging results in measuring inflammation. This new technique holds the potential to greatly increase doctors' understanding of inflammatory mechanisms in early peripheral joint disease.

“Continuous versus on demand treatment of ankylosing spondylitis with Diclofenac over 2 years does not prevent radiographic progression of the spine – results from a randomized prospective multi-center trial.”

Abstract by: Joachim Sieper (Germany)

According to Professor Sieper, the best treatment outcomes in AxSpA patients are achieved when TNF-I and NSAIDs are given early in disease. Evidence suggests that early TNF-I treatment holds potential to slow structural damage. However, it was reported that less is known about the impact of NSAIDs on structural damage. Despite two other studies to the contrary, Dr. Sieper reported that over a two year follow up study, no significant difference was noted in radiographic progression between the continuous use of NSAIDs compared to on-demand use of the NSAID Diclofenac. The study, which included 60 patients, also reported that in fact the “on-demand” group followed a trend of less radiographic progression compared to the “continued use” group, contrary to previous studies.

“The role of a nurse-clinic in the assessment and prevention of cardio-vascular risk.”

Abstract by: Francisca Sivera (Spain)

A recent study reported that nurses can greatly improve cardiovascular (CV) risk outcomes in patients. It was found that risk assessment screening by nurses in patients who had not self-reported CV risk factors revealed the existence of CV risk factors in 75% of patients screened. The increased CV risk in inflammatory arthritis is driven by persistent subclinical inflammation as well as known risk factors including smoking, hypertension, diabetes, weight, and high cholesterol. The study confirmed that with treat to target strategies and monitoring by nurses we could potentially improve patient outcomes coursed by factors previously ignored in rheumatology practices in Europe.

PARE session

“What really works: Engaging health care professionals in supporting patients into work.”

Speaker: Debbie Cohen (United Kingdom)

It has been long known that meaningful work can increase an individual's self esteem, quality of life, and overall health status. Researchers in Europe are currently assessing various

S A A ' s

Executive

Director, Laurie

Savage with Raj

Mahapatra - Chair

of the National

Ankylosing Spondylitis

Society in the UK (left)

and Zhivko Yankov -

Chair of the Bulgarian

Ankylosing Spondylitis Patient

Society (right) at the Ankylosing

Spondylitis International Federation

(ASIF) booth, at EULAR.

Photo credit and thanks: Zhivko Yankov



means to help patients with this goal. Recently 3,500 general practitioners underwent training to help them better engage with patients regarding work and health issues. In addition, five pilot studies involving 120 rheumatologists training in this area have been run. In reviewing the outcome of the studies, we find that physicians have reported increased confidence in being able to engage in complex and more meaningful conversations with patients regarding work, sick leave, reduced productivity due to illness, and performance issues at work, thus giving their patients tools to help stay in the work place.

“The addition of one or more biologics to Methotrexate in children with juvenile idiopathic arthritis increases the incidence of infections and serious adverse events. The 5882 pharmachild cohort.”

Abstract by: Joost Swart (Netherlands)

A recent study of more than 6,000 patients reported that the use of biologics in combination with Methotrexate (MTX) produced the greatest risk for serious outcomes. It was reported from the long term safety data that MTX alone produced the least number of serious side effects over time, followed by MTX plus one biologic, with the incidence rising with the administration of MTX and a combination of more than one biologic in sequence over time. A similar trend was reported for infections and serious infections. The study concluded that over time it would be possible to predict which combinations and which medicines carried a better safety profile.

Additional reporting from EULAR can be found on SAA's website, in our news section. Please see <http://www.spondylitis.org/press> for summaries of the following studies presented at EULAR:

- **Secukinumab - A New Kind of Ankylosing Spondylitis Medication on its Way?**
- **Environmental Triggers, the Epigenome, and Disease Progression in AS**
- **Physical Trauma Associated with the Onset of Psoriatic Arthritis among those with Psoriasis**

Helpful Hints: Keeping Active

Introducing **Helpful Hints**, a new recurring feature in *Spondylitis Plus* dedicated to your helpful hints, tips, and tricks on different aspects of life with Spondyloarthritis.

Have a helpful hint to share with other readers? Send it in and we might publish it in our next issue. Next Helpful Hint topic: Open Forum – anything goes! Please send your hints to Elin@spondylitis.org

We kick off this feature by sharing hints and suggestions from our Facebook friends on keeping active.



We want your tips and suggestions for incorporating more physical activity into our lives! Do you have simple things you do regularly to add movement and stretch? A favorite exercise or fun physical activity you recommend?



Like



comment



Share



Helena S Get in the pool! Everything from floating to water walking to good old fashioned front crawl feels great in the pool.



Bev K Heated pool! Warm water and pool noodles really help! Floating, stretching, and doing core exercises in the warm water really feel great!



Richard H Just moving around helps. Walking breaks are great and clear my thoughts. A quick arm stretch to align my spine and I'm off. I like to stand up whenever anyone walks into my office or when I talk on the phone. My screen rotates so I can stand and type (as I'm doing now.)



Carole G Gardening - a lot of bending and stretching.



Tara S Gardening is great exercise for mind and body; it is also easy to adapt to your abilities!



Filipe P Body Pump & Body Balance. The first for fun and strength the second to heal and stretch! Best time ever in 20 years! Used to have dance classes too (Salsa & Kizomba).



Ken F One thing that helps is to spend time on the floor on my stomach. I end with a lower back stretch that normally will pop my back. This also helps to straighten my forward bending neck.



Sue Ellen T Walking in parks.



Crystal H Squats while I brush my teeth, calf stretches on a curb after a walk, yoga (*if I can't make it to the studio I use an app called Yoga Studio,*) alternate between sitting and standing at work, sit on a fitness ball at home, park farther away from entrances, get off public transport 1-2 stops early and walk the rest of the way, hiking. I don't do all every day though.



Ruth O I never park in the closest spot in a parking lot. I figure every extra step I take is good for me.



Richard H Spinning and cycling give me a great cardiovascular workout and provide resistant weight exercise for my legs/hips. They're my 'prevent heart disease and osteoarthritis' workouts. I have a 3 day/week early morning cycling schedule and never miss a class. I stay cognizant of spine alignment - for me that means hips back over the seat, not too much arch in my lower back and keeping my chest lifted. A sweat drenched workout builds confidence, provides a positive serotonin effect, and can almost always get me past a flare.

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Please note that SAA does not endorse or recommend any specific medications or products for SpA, and always advises that you seek the counsel of a physician before initiating treatment. The opinions expressed in the Helpful Hints feature are solely those of our readers and our community.

Medical Marijuana – The Changing Landscape

As the popularity of medical marijuana continues to rise—as of July 2015, 23 states and Washington, DC, have legalized cannabis for medical use—debate and controversy surrounding the ancient drug remain. Cannabis has been used both recreationally and medicinally for millennia, yet much remains to be learned about the herb, and the question of its medicinal value is sure to elicit strong reactions from supporters and critics alike. Anecdotally, marijuana is said to alleviate a variety of conditions, from nausea and vomiting during chemotherapy to the chronic pain associated with diseases such as multiple sclerosis and spondyloarthritis. But what does research show?

In terms of chronic pain, marijuana appears to work on two different molecules, called cannabinoid receptors 1 and 2, or CB1 and CB2. Studies have shown that CB1 receptors are found throughout the body, particularly in areas of the central nervous system that control pain perception. CB2s are primarily located in areas that control immune function. Marijuana works on these two receptors simultaneously to reduce pain.

Researchers at the University of California, San Francisco found in a 2011 study that patients with chronic pain experienced greater relief when cannabinoids, the main ingredient in medical marijuana, are added to opioid treatments (morphine and oxycodone). In the first human study of its kind, the UCSF team found that the cannabinoid-opioid combination worked better than opioids alone in controlling pain, which resulted in less of a need for the opioid drugs.

A 2015 paper in the *Journal of the American Medical Association*, however, examined 80 different studies with nearly 6,500 participants and found that patients experienced only moderate pain relief from cannabinoids. In addition, they found an increased risk of adverse side effects among users, including dry mouth, dizziness, fatigue, disorientation, and loss of balance, however mild.

Up until now medicinal marijuana research has been scarce, mainly due to restrictive policies governing cannabis research. Until very recently, all proposed marijuana studies - already approved by the FDA as well as an Internal Review Board, as is the standard - had to then undergo additional review by the Public Health Service (PHS), and if approved by PHS follow strict guidelines set by the agency. This additional requirement (which no other controlled substance was subject to) was lifted in June of this year, and thus we are likely to see an increase in medical marijuana research.

What about the medical marijuana user?

In the 23 states, and Washington DC, where medical marijuana use is legal by state law, Federal law still makes using marijuana, regardless of its purpose, illegal. That may soon change as newly introduced legislation would offer protections to these patients. *S.683 – The Compassionate Access, Research Expansion, and Respect States Act of 2015* would, among other things, reclassify marijuana as a Schedule II drug (it is currently a Schedule I Controlled Substance - in the same class as heroin and LSD); it would bar Federal authorities from arresting marijuana users if that use is in compliance with state law, and make it possible for physicians in the VA system to prescribe medical marijuana to veterans in states where it is legal.

The medical marijuana debate certainly continues, but the legal landscape seems to be shifting in its favor.



Did you know?

There are currently two FDA approved synthetic cannabinoid medications used in the US. Marinol (dronabinol) and Cesamet (nabilone) are both made with cannabinoids - the active ingredients in marijuana. Both medications are prescribed to treat or prevent nausea and vomiting caused by cancer medicines, and may have some applications for pain management. Additionally, dronabinol is used to increase the appetite in AIDS patients.

Sources Consulted and for Further Reading:

- <http://thehill.com/regulation/legislation/236797-house-bill-expands-access-to-medical-marijuana>
- <https://www.congress.gov/bill/114th-congress/senate-bill/683>
- <http://www.regblog.org/2015/04/15/chawla-medical-marijuana/>
- <http://www.seattletimes.com/seattle-news/marijuana/how-federal-medical-marijuana-bill-would-affect-washington/>
- <http://www.motherjones.com/mojo/2015/06/marijuana-research-restriction-lifted-obama>
- <http://grants.nih.gov/grants/guide/notice-files/not99-091.html>
- <http://www.deadiversion.usdoj.gov/schedules/>
- http://www.huffingtonpost.com/2015/06/22/public-health-service-review_n_7635760.html

WHAT'S YOUR SAA IQ?

How well do you know us?

What sets the Spondylitis Association apart from other organizations is more than just our programs and services; it's the people. Test your knowledge of SAA's work and the small staff of dedicated professionals who get that work done.



Q. You probably know that SAA was the first nonprofit organization in the US to specifically address the needs of people living with spondyloarthritis. But do you know how long SAA has been leading the fight?

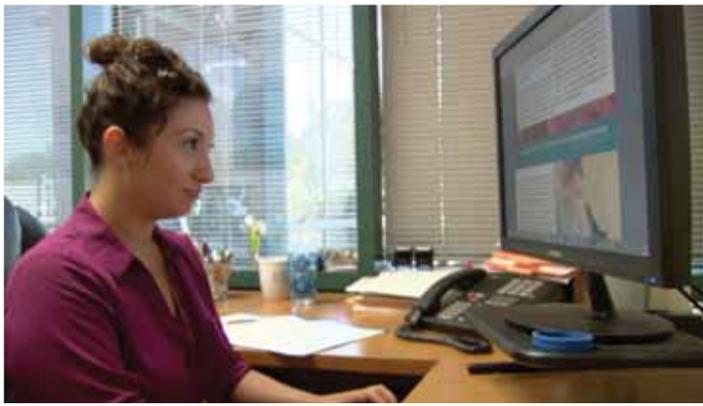
A. When SAA opened its doors in 1983, McDonald's hadn't introduced the Chicken McNugget, Facebook founder Mark Zuckerberg wasn't yet born and "The Newlywed Game" was in preproduction. For 32 years, SAA has been at the forefront of the fight to promote medical research, educate both the medical community and general public, and advocate on behalf of the people we serve.

Bonus Question – Did you know that SAA's Executive Director, Laurie Savage, has been with the organization for almost 20 of those years and counts ocean sailing and flying fixed wing planes among her many talents? *Stay in touch* – laurie.savage@spondylitis.org.

Q. You know that SAA is the leading force behind advances in all areas of spondylitis research and education. How many staff people do you imagine lead this fight?

A. SAA's seven full time staff members have an accumulated 75 years of SAA work time. Such a small turnover is testament to the fact that SAA staffers take great pride in their work and are passionate about what they do!

Bonus Question – Did you know that SAA's Associate Executive Director, Richard Howard, who has been an SAA member since 1993, is a certified Yoga Instructor and often teaches free private sessions prior to his Los Angeles Support Group meetings? *Stay in touch* – richard@spondylitis.org.



Q. Sometimes communicating with someone who knows what you're going through can be the best medicine of all. Did you know that SAA can be your one-stop-shop for connecting to the spondylitis community?

A. SAA can help you get in touch with others to share information and support through our Connections Program. There you'll find an extensive listing of Support Groups all over the country, free online Message Boards, Seminars and Webinars, a vocal and active community on Social Networks like Facebook, Twitter and more.

Bonus Question – Did you know that Elin Aslanyan Gallegos, SAA's Programs Manager and Editor-in-Chief of Spondylitis Plus, who manages many of these programs, recently celebrated her fairytale wedding? *Stay in touch – elin@spondylitis.org.*

Q. There are many charity watchdog groups that assess nonprofits based on a variety of factors. Do you know where SAA ranks?

A. SAA has received a perfect score of 100 for fiscal accountability and transparency every year since Charity Navigator began evaluating these criteria in 2010, and an overall rating of four out of four stars for eight of the last ten years. We're also a top rated Gold Star Participant on Guidestar.org and have a perfect five star rating on GreatNonprofits.org.

Bonus Question – Did you know that SAA's Director of Annual Giving, Diann Peterson, who provides charity watchdogs the information they need to perform their evaluations, loves to travel and has been to 27 countries? *Stay in touch – diann.peterson@spondylitis.org.*

Q. SAA receives no government funding and relies on the generous donations from individuals to create and maintain the programs and services aimed at improving the futures of the **2.7 million Americans** affected by spondyloarthritis. Can you guess how many of those individuals turn to SAA for support in any given year?

A. Spondylitis.org is visited by 1.5 million unique visitors every year. Our Message Boards generate more than 75,000 page views every month. And the most dedicated of these individuals make a financial commitment to SAA each year.

Bonus Question — Did you know that Helene Hart, SAA's Membership Coordinator, who knows almost every member's name and account number by heart, does a little dance at her desk whenever a donation comes in? *Stay in touch – hhart@spondylitis.org.*



Q. Making direct donations isn't the only way to support the Spondylitis Association. Were you aware that Health Advocates and Volunteer Fundraisers lead campaigns all year long to raise awareness for the cause and funds for the cure?

A. There are many ways to contribute to SAA's mission – run a marathon, throw a party, donate auction proceeds through eBay's Giving Works, post a review on GreatNonprofits, create a fundraiser on Crowdrise, join our social media groups, and so many more.

Bonus Question – Did you know that Robin Kindrick, SAA's Executive Associate, who can help get you started on any of these platforms, also has the cutest grandbabies ever? *Stay in touch – robin.kindrick@spondylitis.org.*

Q. SAA is here for you when you need us. Do you know how to reach us when you have a question or concern?

A. Just call 800-777-8189 M-F, 8:00 – 5:00, email info@spondylitis.org at any time, or feel free to contact any of us directly. That's why we're here!

Bonus Question – Did you know that Linda Powell, SAA's Administrative Associate, who keeps an open webcam of an eagle's nest on the corner of her computer monitor, is here to answer your questions or put you through to the person who can? *Get in touch – lpowell@spondylitis.org.*

So, how did you do? Do you know more about your SAA than you did before?



Central Sensitization and its Role in Chronic Pain

By David Yu, MD

Pain: We'd do just about anything to be rid of it. It can take over the body, the mind, and seem to develop a life of its own. But are there different kinds of pain? Different mechanisms at work requiring different approaches? We sat down with Dr. Yu to speak about all of this and more.



Does pain serve a purpose?

A major factor in why the human race has survived is because humans can sense pain.

We sense pain quite frequently in everyday life, e.g. when we touch a needle point by accident. The purpose of this type of acute pain appears to be to prompt us to withdraw from harm.

The purpose of chronic pain, in which the duration exceeds several months, is different. Almost always the cause resides inside of us, e.g. a tumor in the liver or inflammation of the spine. As a matter of fact the simplest explanation for the pain of spondyloarthritis is that it is caused by inflammation in the spine and elsewhere. The apparent purpose of chronic pain is to alert the individual to correct the pathology.

“The sensation of pain is processed by our nervous system. The nervous system consists of three different structures: the brain, the spinal cord, and the peripheral nerves.”

How many people have chronic pain in the US?

As many as 19% of adults in the U.S. are experiencing chronic pain, and half of those report that their pain levels are very high. Surprisingly, at least 1% of adults experience significant and widespread chronic pain when there is no obvious pathology, a condition called fibromyalgia. It is believed that the pain of fibromyalgia is the archetype of what is known as central pain.

What is central pain?

The sensation of pain is processed by our nervous system. The nervous system consists of three different structures: the brain, the spinal cord, and the peripheral nerves. When my finger is in contact with a sharp needle, the pain signal is first transmitted from my finger

“Central pain is not relieved by standard arthritis medications such as acetaminophen, naproxen or even biologics.”

to the spinal cord, then upwards to the brain. At least two compartments of my brain process this signal in the context of all my past experience as well as my current psychosocial state. The human brain, being the most highly developed among animals, is capable of modifying our response to the cause of pain, e.g. keep on running in spite of pain in order to finish a marathon. The command from the brain is then transmitted once more via the spinal cord back to the peripheral nerves. Here, in some cases, sustained pain signaling creates alterations in the nervous system, leading to a lowering of the pain threshold and the enhancement of pain intensity, a process nick-named “wind-up” which involves neurotransmitters glutamate and substance P, among others.

“Wind-up” in both the spinal cord and the brain are responsible for central pain. It is termed “central” because the brain and the spinal cord together comprise the central nervous system. The human mind is an extremely creative structure; it can generate and moderate belief systems, sadness and happiness, courage and cowardice, spirituality or analyticity, dignity or indifference, completely independent of external events. Not only that, the mind which the brain generates, differs from person to person, varies from hour to hour, with an infinite degree of variety. With the onset of modern technologies, such as functional MRI, it is now believed that central pain is generated partly by our central nervous system itself, disproportional to outside events both in intensity and in duration. When a patient with arthritis senses disproportionately enhanced pain relative to the extent of arthritis, the process is termed “central sensitization”.

What is the role of central pain in arthritis?

Although the pain of arthritis is initiated by inflammation of the musculoskeletal system, central pain becomes a critical factor when the central nervous system modifies the sensation of pain to become disproportional to the degree of inflammation. I have seen for example patients with severe and active rheumatoid arthritis who feel very little pain. More frequently, I see patients with minor inflammation who are in severe pain. The prevalence of central pain in arthritis is best studied with rheumatoid arthritis - about

~ Opiates ~

New Rules May Make it Harder for Patients to Get Powerful Painkillers

Last year, the federal government instituted new regulations that restrict the number of hydrocodone combination painkillers (HCPs) that patients can receive from their doctor at any one time, a move that may make it more difficult for patients with spondyloarthritis and other conditions to get relief from their pain.

Under the Controlled Substances Act, the US Drug Enforcement Administration elevated HCPs from a Schedule III drug to a Schedule II drug in October 2014. Schedule II drugs have an accepted medical use, but also can be highly addictive and have a high potential for abuse. Since 1971, hydrocodone alone has been listed under Schedule II. HCPs combine hydrocodone with other analgesics such as aspirin, ibuprofen or acetaminophen and include drugs commonly prescribed to treat spondyloarthritis, including Vicodin.

Patients are now limited to an initial 90-day supply of HCPs (vs. a six-month supply, with up to five refills) and are required to see a doctor for a new prescription each time they need a refill. Phone-in refills are no longer allowed, and most states require that a doctor, not a nurse or physician’s assistant, write Schedule II prescriptions.

According to the Food and Drug Administration, hydrocodone is the most prescribed opiate in the United States, with nearly 137 million prescriptions in 2013. Deaths from overdoses more than tripled from 1999 to 2010, a period during which sales of opiates rose four-fold.

The DEA says the changes are geared toward minimizing misuse of HCPs for recreational purposes, while still allowing patients access to the amount of drugs needed to relieve their pain. Critics argue that the rules may lead some patients to seek problematic alternatives, such as Tylenol with codeine, which can cause liver problems, or turn to the black market for pain relief.

Editor’s Note: What are your thoughts on and experiences with these regulations? Have you been impacted by them and have a story to tell? Send us your thoughts on the topic and we may print them in the next issue of *Spondylitis Plus*.

CHRONIC PAIN

25% of patients with rheumatoid arthritis also have features of central pain/fibromyalgia. That number is lower in ankylosing spondylitis, with about 15% of AS patients having central pain/fibromyalgia features.

How important is it to determine if central pain contributes to the suffering of an arthritis patient?

It is critical for a physician to distinguish central pain from pain caused by the arthritis alone. Central pain is not relieved by standard arthritis medications such as acetaminophen, naproxen or even biologics.

How do doctors diagnose central pain?

Extreme central pain as we see in fibromyalgia is easily recognized by several features. (1) Pain is widespread. Patients usually describe the pain as involving the entire body. (2) It is associated to varying degrees with feelings of exhaustion, being un-refreshed after waking up from sleep, and lack of clarity in thoughts. (3) It is often associated with mood changes such as depression and anxiety, and somatic complaints such as headache, diarrhea, and bladder spasm.

Other than the pattern of symptoms, there are no physical signs, laboratory tests, or clinically applicable imaging tools to diagnose fibromyalgia.

Can fibromyalgia be misdiagnosed as spondyloarthritis?

In general, rheumatologists are physicians who are familiar with both fibromyalgia and spondyloarthritis. They diagnose fibromyalgia and spondyloarthritis by the patterns of symptoms, physical signs, laboratory tests and imaging tests. For both spondyloarthritis and fibromyalgia, even negative laboratory tests and imaging tests, as well as negative physical signs, are important. However, there is no infallible diagnostic formula. The ultimate decision depends on the judgment of the physician.

A major challenge is that both fibromyalgia and spondyloarthritis are spectrums of disorders. The patterns of diseases can be florid or subtle. In addition, regardless of having fibromyalgia or not, in any subject, all pain is colored by past experiences, current events, future aspirations, moods of depression or anxiety, and even purposefulness in life. How a physician interprets reports of pain by a particular patient is also colored by the physician's own experiences and sense of selfness.

~ Tylenol ~ Acetaminophen and Liver Damage

In the United States, acetaminophen (e.g., Tylenol) is the most commonly used medicine for pain relief. This over-the-counter drug, often used as an alternative to nonsteroidal anti-inflammatories like ibuprofen that can cause gastrointestinal bleeding, is used to treat mild to moderate pain from backaches, headaches, sprains, arthritis and menstrual cramps. Acetaminophen (called paracetamol in most of the rest of the world) is the go-to pain medication for many spondyloarthritis patients, especially those who have difficulty tolerating NSAIDs.

While acetaminophen is safe and effective when taken at recommended doses, new evidence suggests that prolonged exposure to the drug—like that experienced by people with chronic pain—can lead to liver damage. In fact, the US Food and Drug Administration says acetaminophen is the most common cause of acute liver failure, in which the organ fails quickly, sometimes in less than 48 hours.

The human body processes acetaminophen in one of two ways. Drug molecules in the bloodstream attach to sugars and sulfates that allow the drug to be removed from the body in bile. This occurs when the drug is taken at recommended doses. When taken in higher doses, enzymes that mop up a toxin produced by the breakdown of the drug are overwhelmed and cannot work effectively—which puts the liver at risk.

Because the drug has been considered so safe, people often take more than the recommended dose—thinking more could be better—putting themselves at risk for adverse events.

Until more is known definitively about the negative long-term effects of acetaminophen or until a new drug is created, such as one that targets the toxin-chomping enzyme, patients' best bet is to carefully read warning labels, follow recommended doses, and consult with their doctor if they have questions.



Not infrequently, a single visit to a physician is insufficient. Often times the true diagnosis will unfold with time.

Can changes in mood affect the sensation of pain?

There is a great deal of variations among patients. In general, even with patients carrying an irrefutable diagnosis of spondyloarthritis, changes in mood can affect the severity of pain felt regardless of whether or not a spondyloarthritis patient is being affected by central pain. As emotion is part of the constitution of a person, a patient should be aware of their mood, and whether changes in mood affect the severity of their pain.

“The most effective modality for alleviating central pain is exercise. The exercises should preferably be of an aerobic type, such as fast walking for 20 minutes, three times a week.”

Are there medications for central pain?

Several drugs have been approved by the FDA for the treatment of fibromyalgia. About one in ten to one in five patients might experience a 30% or more improvement in pain with these medications. In treating central pain, it is best to combine medications with non-pharmacological measures.

Which non-pharmacological measures are useful for control of central pain?

Non-pharmacological measures for central pain are useful for all patients with spondyloarthritis pain, regardless of the degree of contribution by central pain mechanisms. I advocate all patients to consider them seriously. An ideal management of central pain is an interdisciplinary form of pain management. The first step is education about spondyloarthritis, which is what the Spondylitis Association of America is providing.

The most effective modality for alleviating central pain is exercise. The exercises should preferably be of an aerobic type, such as fast walking for 20 minutes, three times a week.



Another useful modality is to train patients to recognize how their perception of pain is modulated by their mood, and how the mood leads to changes in behavior. For example, a depressed individual may feel more pain than they normally would, and become more withdrawn in an apparent attempt to avoid pain. This mood-behavior pattern leads to a vicious cycle. The training to break the cycle is termed “cognitive behavior therapy,” and is commonly practiced by psychologists. In a way, support groups are a form of cognitive behavior therapy.

Cognitive behavior therapists also use mind exercises. Examples of this would be relaxation exercises such as meditation, breathing exercises, and imagery. When properly carried out, relaxation exercises lighten the anxiety and depression related with central pain and help break the pain cycle. Training in these relaxation exercises can be expedited by biofeedback.

What is the most important message in this Q & A?

If you are not sure, ask your doctor how much of your pain might be from central sensitization.

Dr. Yu is an Emeritus Professor of Medicine at UCLA. He has been specializing in Spondyloarthritis since 1980. Besides SpA, his main clinical interest is how his patients' pain is affected by cognition and emotional regulation. He is the main author of the section on AS in UpToDate, past chairman of SAA's Medical Advisory Board, one of the founding executive committee members of SPARTAN, and a member of ASAS.



HOW IT FEELS

We asked our Online Community to talk about pain. To share what it feels like on a high pain day. Some of the comments we got are heartbreaking, but sometimes it helps to hear that others truly understand our pain

“Bad days make me want to stay in bed, especially when I can barely put socks on. Those days remind me to move it or lose it. Today, I’m okay, thankfully.”
~Dan

“My severe days also equal terrible irritability, brain fog, and massive fatigue. Of course the pain too, which only us spondies know. Today is manageable.”
~Trish

“Some days I do my best to just bear it, ignore it, focus on living, but some days my pain wins - and I struggle to keep my mind positive and just want to cry.....which on occasion I do.”
~Faith

“On a high pain day, I cannot function. I can’t think, move or really do anything except suffer through it. It feels like my entire body is overblown. If something stresses me out, my brain shuts down and my pain gets worse. I have to be really careful not to get upset or let stress get to me. Stress is a major trigger.”
~Carrie



"I didn't know my son took this photo until this morning when downloading from my camera. This was two weeks ago when I was barely able to get out of bed due to AS. Makes me want to cry thinking about what might have been going through his thoughts that made him decide to take the picture."

~ Melissa L. Face #1066 from The Faces of Ankylosing Spondylitis project.

**Photo credit, Melissa's 12 year old son. Originally posted on the Faces of AS website.*

“Bad days felt like grizzly bear claws and teeth ripping through my connective tissue and joints. Last few years have been so much better with Enbrel, warm pool exercises, and walking. I also started deep meditation - this I will never stop! I have become so much better at coping with my AS and have less pain. I can do more pool days and walking now - which decrease my body-wide pain and increase my mental happy mood.”

~Sandy

“On a high pain day, I feel like I just woke up after being hit by a truck. That is the best way I can describe it.”

~Colin

“I get pins and needles all over my body, and anxiety through the day because of it. I think, “how will I go on through the day and not let anyone know this is what I’m feeling?” An ache in my neck and collar bones so bad that I can barely keep my head upright. It’s an ache that no medicine can touch. I feel like I’m the only person in the world where a simple hug from someone can hurt me the rest of the day (and I loved hugs.)”

~Janice

“After suffering pain for 39 years, I finally went to a Rheumatologist today. After thinking all these years I just needed to “buck up” and get through this, today has been a day of acceptance for me. Thank you for all your comments. The feeling that I’d been run over by a truck was validated here by several of you. And the severe pain I experience was in so many of your comments.”

~Vicky

What about the emotional aspect of chronic pain?

“Don’t forget the emotional pain of having our lives taken over by this illness: Having to miss events, parties, playing with the kids. But the worst thing this monster did was robbing me of playing the guitar. I had a knuckle replacement in my left hand that stopped me from playing.”

~Stuart

“I think half the battle each day is emotional/ mental. I hate it when the pain makes me an unpleasant person to be around. I don’t want to be defined by this illness but it invades every aspect of your life and I don’t know how to take back control. I am controlled by pain and at the mercy of modern medicine.”

~ Shuree



Your Stories:

Hillary Norton, MD

Hillary Norton, MD is a board certified rheumatologist in Santa Fe, New Mexico and herself an ankylosing spondylitis patient. This is her story.

Spondylitis patients are known to experience a delay in diagnosis, often as long as 10 years. So why, in 2015, are these diseases still underdiagnosed and undertreated? One key factor is that the age of onset is young: The average onset age falls in the mid 20s. People in their 20s don't typically go to the doctor for back pain. They often assume it is a result of athletic activities or physical work. If it gets bad enough to seek treatment, it will often be with a chiropractor, a physical therapist or a sports medicine doctor. And we know that these practitioners are often not thinking about spondylitis. It's a common story. Someone has back pain that is presumed related to workouts. It gets severe enough to start interfering with sleep. A sports medicine doctor is consulted who diagnoses an SI joint sprain, and physical therapy is recommended. It may or may not help, because the symptoms tend to wax and wane early in the disease. Several months later, a shoulder injury due to weight lifting is diagnosed. The patient is sent back to physical therapy. The physical therapist notes that this is not responding the way a sports injury generally would and wonders what the real issue is. But, when you're young, you go on and don't give it much more thought.

This is a common story, and this is my story. I had back pain for 10 years prior to diagnosis, and only when the pain started to interfere with my life did I look into it. When there were no answers to be found I tried to ignore it, and forget that it was there. Then, as often happens, an event occurred which brought me to the attention of the appropriate specialists.

I was a first year, first month internal medicine intern on an ICU rotation with a 30 hour shift. It was July 1, 2007 and my first day – no stress there! We had a code blue called outside the building, meaning that a patient was having an emergency and potentially required resuscitation. We ran with our code equipment into the bright sunlight and when the light hit my

eye, it was like an ice pick in my brain. I told the ICU fellow that something was wrong. I had photophobia. He said, “No you don’t, you have a 30 hour shift to work.” By the next morning my eye looked like a hemorrhage had happened. My senior resident saw me and asked what happened, but didn’t wait for my answer as she picked up the phone to page ophthalmology. She told them, “We have an emergency with an intern.” She knew that uveitis is one of the leading causes of blindness if untreated. The astute ophthalmologist took me to his clinic for an exam and asked if I had back pain. I said sure, but I’ve had that for 10 years or so. He said you need a rheumatology evaluation. I barely knew what rheumatology was – we don’t get much exposure to it in medical school. Perplexed, I wondered how my back pain could possibly be related to my eye pain. After visiting the rheumatologist, a lot of pieces came together as I got the diagnosis of ankylosing spondylitis. We don’t talk much in medical school about the systemic symptoms in AS, but the flares with low grade fevers, joint pain, and severe fatigue are fairly common.

“ I barely knew what rheumatology was - we don't get much exposure to it in medical school. Perplexed, I wondered how my back pain could possibly be related to my eye pain. ”

Soon after diagnosis, treatment options were discussed. Like many of my patients now, I was afraid of biologics. I waited long enough that I have a good understanding of the natural progression of this disease. Eventually I was limping around the hospital as a rheumatology fellow. Many days I couldn’t do the stairs; I would take the elevator and then try to catch up with my team on the wards. My nights became shorter and shorter as I could no longer lie down for more than a few hours. My husband would help me out of bed in the middle of the night, which was a process that took some time. I would then pace slowly or sit upright in a chair for the rest of the night. Rock bottom came when I was traveling and in a hotel room without my husband. Two hours was the extent of my sleep that night and then I had to get up. The problem was I just couldn’t do it. I was stuck in bed in a hotel room and unable to get up, yet lying down meant pain too severe to handle. I realized then that it

“ Two hours was the extent of my sleep that night and then I had to get up. The problem was I just couldn't do it. I was stuck in bed in a hotel room and unable to get up, yet lying down meant pain too severe to handle. ”

was time to try a TNF inhibitor. I did my first injection and boy was I ready. I thought bring it on! The very next day I awoke in the morning – the morning! Not the middle of the night! I thought my husband was asleep and I got up and took a few steps. I turned to look at him and his jaw was hanging open. He said, “You just got up!” I said, “I know, I just got up!” It was like turning the clock back. I will never forget that morning. Every time I sit up and swing my legs out of bed I am still grateful that I can do that.

This journey with spondylitis has helped me understand what my patients are experiencing - this is something you cannot learn from a textbook. We have treatments for this disease that work for many, and promising new ones in the pipeline that I hope will prove effective for countless others. Spondylitis is getting more exposure in recent years and I am hopeful that we will continue to make strides in earlier diagnosis and better treatments to help change lives.

Hillary Norton, MD completed her medical school training, as well as internal medicine residency and rheumatology fellowship at the University of New Mexico. She is board certified in both Internal Medicine and Rheumatology. She currently runs a busy solo private practice in Santa Fe, New Mexico. She is a member of the American College of Rheumatology and the New Mexico Medical Society. She is a clinical investigator for several rheumatology disease registries. She has co-authored papers in Arthritis and Rheumatism, the Journal of Rheumatology and other peer reviewed journals. As both a spondylitis patient and physician, her passion is furthering education and awareness of spondylitis, particularly in women. Along with her practice staff, she also volunteers with her local chapter of the Arthritis Foundation. During her leisure time, she enjoys running, yoga, cycling, and hiking with her husband and two dogs.



New Website

Spondylitis.org: The Next Generation

In 1966, an iconic American television show, Star Trek, made its debut. Many of the technologies that appeared in the series seemed impossible at the time. One of them was “the communicator.”

For those unfamiliar with the show, the crew of the Starship Enterprise could pull a small device off their belt, flip it open, and instantly communicate with other crew members – no matter their location, or the location of the person they wished to reach.

Today, “the communicator” is reality; our smart phones are that and more. We can instant message around the globe, watch movies, make calls instantly, and browse websites on the internet - all from our personal communicators.

Thus, our Spondylitis.org website is becoming “communicator friendly.” We’ve noticed the number of visitors coming to SAA’s website via smart phones and tablets has more than doubled in the last few years. We want to give everyone – especially our generous donors and members - the best possible online experience no matter the platform / device they prefer.

The new site will continue to advance SAA’s core mission of serving you – our spondylitis community, as well as our undiagnosed in search of answers; continue helping you connect with others in the community; continue to educate patients, families, and friends; continue raising awareness for medical professions, the media, and the general public; as well as offering resources to ease the day to day challenges of spondyloarthritis. Rest assured that our new site will remain your hub for all things SpA, but will now adjust in size and format to any device so that all of its features are easy to access on any phone / tablet.

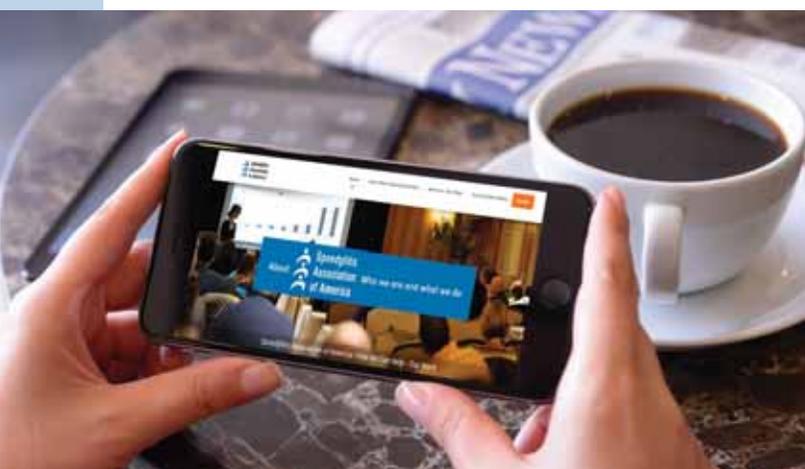
In addition, the new site will include updated resources, such as:

- An updated overview of spondyloarthritis from Dr. Jessica Walsh
- A new section dedicated to Juvenile Spondyloarthritis
- Articles on “The Heart in AS” as well as an in-depth explanation of bloodwork in spondyloarthritis, both by Dr. Lianne Gensler

And more.

So pull out your communicator and visit Spondylitis.org: The Next Generation to see the new features we have to offer.

We’ll see you online at Spondylitis.org.





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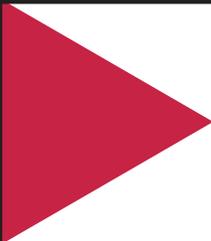
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