SpondylitisPLUS

SUMMER 2020

BIOLOGICS, SPONDYLITIS AND COVID-19

SHIFTING LANDSCAPE OF NUMBERS: WHO HAS SPA IN THE U.S.?

HOW TO GET MOVING WHILE STAYING HOME

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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CHIEF MISSION ADVANCEMENT OFFICER
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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:

Is it just me or does time seem to be moving at different speeds than it used to? In some ways this seems like the longest summer I can remember, and in other ways I can't believe it's coming to a close! This summer issue of *Spondylitis Plus* is coming to you later than we'd planned, in large part because SAA has had some of the busiest months in recent memory.

In the last six months, we've moved to an entirely cloud-based computer system; traded desktops for laptops; embraced the Zoom meeting; installed phone apps so that our incoming calls are routed to our homes; and settled into the new routine of working remotely. We've also just completed moving our office to a beautiful new location better suited for today's needs. *(Watch this space for upcoming pictures and details about SAA's new home.)*

More importantly, we've authored a complex, scientifically vetted COVID-19/SpA survey (please see page four of this issue) and numerous articles answering our community's most pressing COVID-19 questions; launched a brand new website; presented informative educational programs via Zoom and Facebook Live; produced Continuing Medical Education programs geared to First Responders, Nurses, and Chiropractors; hosted our second annual Global Spondyloarthritis Summit; translated several of our educational brochures into Spanish; debuted an updated version of our Community Forums; and so much more.

And, as always, we've continued to connect directly with our community each and every day. Our nationwide network of Support Groups is now meeting virtually and we have plans to grow and expand the program now that geographical barriers are less of a concern. *(If you're interested in joining a group, or even starting one of your own, there's never been a better time. Contact us at Programs@spondylitis.org today to learn more!)*

It's been a wild ride and one not every organization could have kept up with. One of the things that has resonated with me in the three years since I joined SAA is its ability to turn on a dime and handle whatever is thrown at it. It's rare to see an organization that is so established and solid, but also so nimble. I believe that trait has served us, and you, well.

I want to thank you for your continued support during these challenging times and remind you that SAA is still here, still working for you, and because of you, stronger than ever!

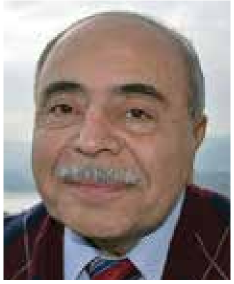
Cassie

Cassie Shafer
Chief Executive Officer

READER'S FORUM:

"SEMPER FIDELIS" and the HLA-B27 Gene

by Muhammad Asim Khan, MD



It was 28 years ago that a U.S. Marine Corps officer injured his back while skiing which necessitated his being seen at a health care facility. He received treatment and very soon fully recovered to resume his training as a naval pilot.

But to his utter surprise, he was told that he was not suitable for further training as a naval pilot because he possesses the HLA-B27 gene which evidently makes him prone to developing ankylosing spondylitis.

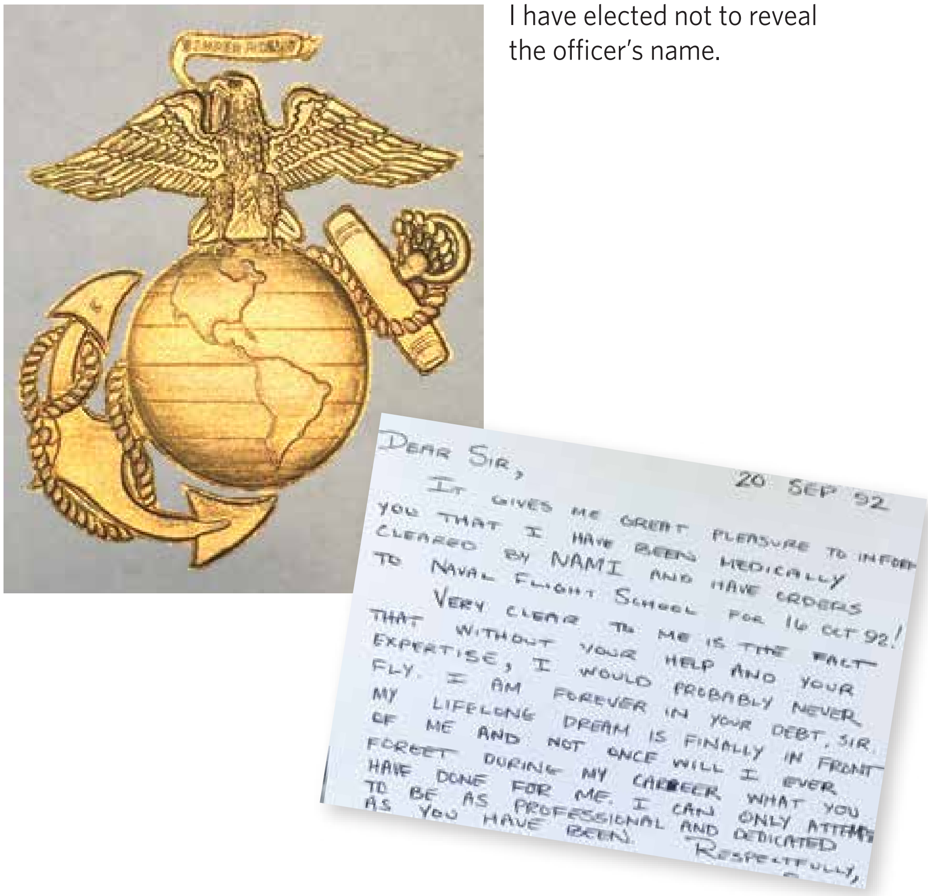
He contacted me about his positive test result. On detailed discussion it was obvious to me that there had been no clinical reason in the first place to order this test.

I made him aware that, based on his ethnicity, he carried an 8% chance of possessing the HLA-B27 gene as a perfectly healthy individual. I also told him that more than 95% of the individuals possessing this healthy gene in the general population never develop ankylosing spondylitis.

I promised to provide him with all the help and information in order to force the Marine Corps to reverse this wrong decision.

Finally, there was a happy ending!

One of my proud possessions is the letter I received from him later that year with the golden embossed emblem of the U.S. Marine Corps, as shown in the picture. The eagle proudly carries a streamer in its beak that bears the motto of the Corps: Semper Fidelis. (Always Faithful)



DEAR SIR, 20 SEP 92
IT GIVES ME GREAT PLEASURE TO INFORM
YOU THAT I HAVE BEEN MEDICALLY
CLEARED BY NAMI AND HAVE ORDERS
TO NAVAL FLIGHT SCHOOL FOR 16 OCT 92!
VERY CLEAR TO ME IS THE FACT
THAT WITHOUT YOUR HELP AND YOUR
EXPERTISE, I WOULD PROBABLY NEVER
FLY. I AM FOREVER IN YOUR DEBT, SIR.
MY LIFELONG DREAM IS FINALLY IN FRONT
OF ME AND NOT ONCE WILL I EVER
FORGET DURING MY CAREER WHAT YOU
HAVE DONE FOR ME. I CAN ONLY ATTEMPT
TO BE AS PROFESSIONAL AND DEDICATED
AS YOU HAVE BEEN.
RESPECTFULLY,

I have elected not to reveal the officer's name.

CONTENTS:

Dr. Atul Deodhar climbing Mt. Hood just before granting us the interview on pg. 10.

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.

Recap of Major Findings by Study Lead Author, Dr. James Rosenbaum:

"What do COVID-19 and spondyloarthritis have in common? One answer is that they both involve the immune system. Whether you develop COVID-19, and how severe that infection is, depend on your body's immune response. And, of course, spondyloarthritis is a group of diseases in which the immune system attacks the spine and sometimes tendons, other joints, eyes, and intestines. Common treatments for spondyloarthritis include medications like biologics (for example, Enbrel or Humira), NSAIDs (non-steroidal anti-inflammatory drugs like Advil or Aleve), and other choices that usually target inflammation or the immune system. So, patients and medical providers need to know if these medications might be harmful by increasing the risk of contracting COVID-19 or the risk of developing life-threatening COVID-19.

To address these questions, we worked to design a study, and then reached out to our patient community. More than 4,000 people have thus far participated in the web-based survey, which is still ongoing. **The bottom line: the survey found no evidence that biologics like TNF or IL-17 inhibitors, NSAIDs, or medications like methotrexate increased the risk of contracting COVID-19 or the risk of developing more severe COVID-19."**

Spearheading Research on COVID-19 and Spondyloarthritis

Back in the early days of this pandemic, one of the most unnerving things about COVID-19 for many in our community was the uncertainty around what effect having spondyloarthritis may have on the risk of contracting COVID-19, or of developing severe symptoms. Did having spondyloarthritis put our community in the high-risk category?

And what about taking medications like biologics? Or NSAIDs such as ibuprofen? Were these medications now high-risk to take? And should you come off your medication?

We received countless variations of these questions, and consulted the brightest, most knowledgeable minds in the spondyloarthritis research world for answers and guidance. (Special thanks to Dr. John Reveille for being our go-to explainer of existing research and basic immunity principles, and for providing guidance and leadership surrounding these questions where there was a vacuum of helpful information and direction.)

Thanks to Dr. Reveille and others on our medical board, we had some very good answers and general guidance on these questions, but we still didn't have a specific research study on COVID-19 and spondyloarthritis to point to. And we're used to answering questions with studies! So, we decided to conduct one ourselves.

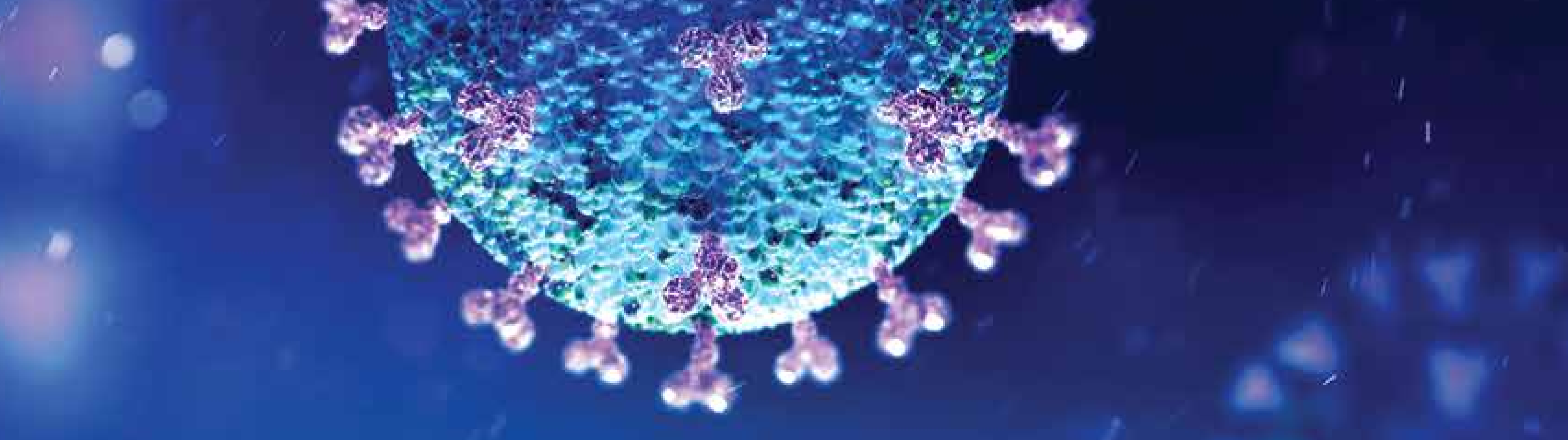
We worked with a dream team of passionate and committed investigators, under the guidance of rheumatologist and researcher, Dr. James Rosenbaum, and developed a multifaceted and robust research survey, to include not only patients, but also a control group consisting of people who didn't have SpA, living in the same household.

We connected with the CEO of a truly world class survey platform company, Any-3 Ltd's Hedley Hamilton, who was generous beyond measure in leading his team to create the technical magic required for this complex survey. Hedley and his team donated untold hours of work developing the back-end content to enable us to track patients and their household members as they went through different phases of this study. We simply can't thank them enough! We also thank the Axial Spondyloarthritis International Federation (ASIF) for their support in extending our reach to our global spondyloarthritis community.

But above anyone else, SAA thanks our community for giving of their time and energy during these difficult days to complete the survey, and continue to take part in monthly follow ups.

The following article, published in the very prestigious peer-reviewed journal, *Annals of the Rheumatic Diseases*, and the knowledge gained through the survey, simply wouldn't exist without YOUR involvement and generosity. So, from the bottom of our hearts, thank you! And please continue to answer our call to complete our follow up surveys. Without you, this research stops, and there are still so many questions left to answer!

Haven't taken part yet? You can still get involved! Begin your survey today at **spondylitis.org/research/participate-in-research**.



BIOLOGICS, SPONDYLITIS AND COVID-19

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The COVID-19 pandemic has been especially challenging for patients with rheumatic diseases because immune-mediated diseases, as well as their treatment, could adversely impact susceptibility to or severity of a viral infection.[1][2] A recent study from New York City on 86 patients with COVID-19 infection and a history of immune-mediated disease seemed to show that the use of methotrexate, oral glucocorticoids or hydroxychloroquine increased the risk for hospitalisation,3 although the authors still concluded that the overall risk for hospitalization is comparable to that described in the community. Since data to advise patients on these issues are scant and inconclusive, the Spondylitis Association of America (SAA) is conducting a survey to gather information from patient experiences.

The SAA contacted by email nearly 40,000 individuals who had previous interaction with the SAA. Between April 10, 2020 and May 7, 2020, 2,992 patients completed an online survey and reported a history of spondylitis confirmed by a physician. The survey had been approved by the Institutional Review Board of the Oregon Health & Science University. The respondents included 85.0% with ankylosing spondylitis, and others with additional forms of spondyloarthritis such as psoriatic spondyloarthritis. Of those patients who knew results of human leukocyte antigen (HLA) typing, 76.1% were HLA B27+. The respondents included 1,104 men, 1,838 women, 8 whose gender was non-binary, and 42 not providing gender information. The median age was 53 for women and 54 for men. Eighty percent were from the USA, while other respondents were from 64 other countries. Two hundred twenty-three (7.6%) of 2,950 respondents believed that they had been exposed to COVID-19. Thirty-nine (1.3%) believed that they had been infected with COVID-19, of whom 14 (35.9% of those with presumed COVID-19) had confirmation by laboratory testing. As not everyone has access to testing for confirmation, we based our analysis on either confirmed or presumed infection4 as is the current practice of the Oregon Health Authority.

Table 1 and **Figure 1** analyze patients according to class of medication taken for spondylitis with some individuals taking more than one class. The figure indicates that roughly one in four patients on a biologic (25% for antitumor necrosis factor (TNF) or 23% for anti-interleukin 17 (IL-17)) reduced their medication (either eliminated, reduced the dosage or reduced the frequency) because of concerns about COVID-19. The changes are prior to acquiring the actual infection. The table shows that several of the same medications that are feared to increase susceptibility to COVID-19 (antimetabolites, corticosteroids, anti-TNF, anti-IL-17) are actually associated with a rate of COVID-19 lower than or equal to 1.3% for the group as a whole. The reduced likelihood for developing COVID-19 for those taking anti-TNF or an antimetabolite is not statistically significant (p>0.05). Ironically, one class of medication that was associated with risk above 1.3% is antimalarials, but too few patients took this class to provide definitive results.

TABLE 1

Impact of medications on C19

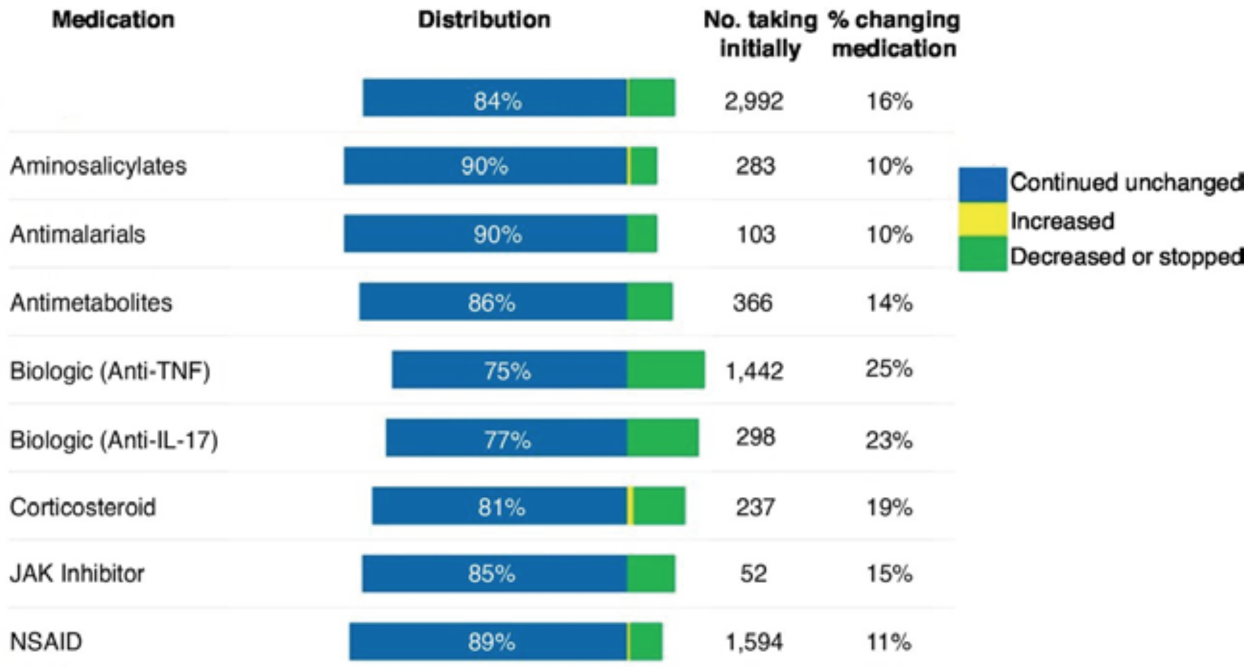
Medication class	Number taking	% with C19
Aminosalicylates	283	0.7
Antimalarials	103	3.9
Antimetabolites	366	0.5
Biologic (anti-TNF)	1442	0.8
Biologic (IL-17)	298	1.3
Corticosteroid	237	0.4
JAK inhibitor	52	1.9
NSAID	1594	1.3
No medication	230	3.5

- *Number taking includes those who altered the dosage or discontinued the medicine as a result of COVID-19. C19=COVID-19. Percents are based on those with either definite or presumed COVID-19.*
- *IL-17, interleukin 17; JAK, janus kinase; NSAID, non-steroidal anti-inflammatory drug; TNF, tumour necrosis factor.*

FIGURE 1

Reduction [was seen] in medication taking across all patients, 16% have changed their medication, primarily reducing or stopping entirely. This is the highest with biologics for which 25% of 1,442 patients on antitumor necrosis factor (TNF) and 23% of 298 on anti-interleukin 17 (IL-17) made changes. NSAID, non-steroidal anti-inflammatory drug; aminosalicylates include sulfasalazine and mesalamine; antimetabolites include azathioprine, methotrexate and mycophenolate. Note that percent changing medication also includes those who increased the dosage, but increasing dosage was rare.

Reduction in medication taking across all patients, 16% have changed their medication, primarily reducing or stopping entirely.



Medication	Distribution	No. taking initially	% changing medication
	84%	2,992	16%
Aminosalicylates	90%	283	10%
Antimalarials	90%	103	10%
Antimetabolites	86%	366	14%
Biologic (Anti-TNF)	75%	1,442	25%
Biologic (Anti-IL-17)	77%	298	23%
Corticosteroid	81%	237	19%
JAK Inhibitor	85%	52	15%
NSAID	89%	1,594	11%

James Todd Rosenbaum et al. Ann Rheum Dis
doi:10.1136/annrheumdis-2020-217941

Surveys are not reliable instruments to determine if the disease itself predisposes to infection since there is inherent bias as to who responds to the survey. However, we did obtain a modified Bath Ankylosing Spondylitis Disease Activity Index from respondents and found little correlation between spondylitic disease activity and severity of COVID-19 as graded by days of disease, probability of hospitalization, or subjective scoring of severity (data not shown).

Although our numbers of subjects infected by COVID-19 are small, the trend showing reduced infection for those on anti-TNF or antimetabolites provides reassurance to patients and providers regarding the safety of several classes of medication frequently prescribed to treat spondylitis, psoriasis and other immune-mediated diseases. Our survey is designed to capture longitudinal patient data and data from household contacts. This prospective approach should provide additional, future insight as to how spondylitis and the medications taken for this illness potentially affect susceptibility and severity of COVID-19.

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Contributors: All authors except DC contributed to the design of the study. JTR, HH and DC performed the data analysis. JTR wrote this report. All authors critically reviewed it and edited it.

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Ethics approval: This study was approved by the IRB of the Oregon Health & Science University, Study00021375.

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GET TO KNOW MANNY CARO, DEVELOPMENT & ANNUAL GIVING MANAGER!

Manny Caro joined the SAA Development Department in the Summer of 2018. Since then, he has been in touch with almost every SAA member! Chances are you have heard from Manny via phone or email. SAA thought it was time for everyone to learn more about this charismatic and helpful person.


Manny Caro

Where did you grow up and go to school?

I was born in Los Angeles and grew up in the San Fernando Valley. I grew up playing Pop Warner football until I was old enough for high school football, which I played at Grover Cleveland High School in Reseda, California. I graduated in 2006. After high school, I earned my associate's degree from Los Angeles Pierce College. Afterwards, I transferred to California State University, Northridge, where I earned my bachelor's degree. Currently, I am working towards a new degree. I have not yet decided on the primary focus of my advanced degree. I am certain, it will be in a field that will allow me to continue helping others for the duration of my life.

What are your hobbies?

My father is an avid outdoorsman. I grew up off-roading, backpacking, camping, fishing, boating, now all personal hobbies of mine. I love being outdoors! Hitting the open road on a motorcycle is also one of my greatest joys. Also, music! I love to play the guitar, the piano, and any other instrument I can get my hands on. Fitness is also very important to me. I am an avid and active boxer. Along with weightlifting, boxing is one of my favorite ways to stay in shape.

What else should readers know about you?

When you call SAA, there is a high probability that I will be the one answering the phone. So, do not be shy and say hello. If you call-in one day, after reading this, you can say, "hey! I read about you in ***Spondylitis Plus***." Also, I am a huge Dallas Cowboys fan and big animal lover (I do not kill spiders). I own over 20 guitars and my collection is still growing. I enjoy working on my car, truck, and motorcycle. I'm also a parent and of course enjoy my time with my son.

The last 6 months have seen huge changes at SAA. What have you heard from our members?

Working from home is new to me, but SAA's leadership made sure I had everything I needed to be able to run at full capacity. The dedication and extra strides taken by SAA's leadership to ensure that we are still able to serve our community even in a pandemic was incredible. I felt fully supported and confident that I can still provide the same quality service that I was able to provide before COVID-19. Most members cannot even tell that SAA staff are working from home. Many are surprised to hear that we are working from home and do not notice until they hear my dog Luna bark at the mailman dropping off the mail. SAA is truly dedicated to serving its population. The first question we asked ourselves was how we can provide our constituents with all the necessary information they need to get through this pandemic. And the answer was: "Keep doing what we do, just do it socially distanced!"

What inspires you to do the important work we do at SAA?

The people who contact SAA every day. Many of the folks who call in or email us have become my friends. Some have even stopped by the office to say hello. Often when they call, it really does feel like a good friend is calling me to say hello. Being able to provide help to someone really inspires me to come into work every day.

Tell me about a few volunteer fundraisers that you have worked on.

Kathleen's triathlon in Alaska and Suna's benefit show in Texas. I identify with their stories so much because I am both an athlete and a musician. Kathleen and Suna refused to let their AS stop them from doing what they love to do, to compete and perform. As both an athlete and a musician, I completely understand their motivation to not let anything stop them from doing what they love.

Do you like helping people on the phone and email? What do you enjoy about those interactions?

I genuinely enjoy both because I thoroughly enjoy the interactions with those who call in or email SAA. I know I have had a good day when I have been able to answer a question or provide a resource to someone who has contacted us. Hearing their frustrations being lifted from their shoulders really puts a smile on my face.

SAA is lucky to have a bilingual staff member in Development. Tell me about working on the JSpA brochure, translating it into Spanish.

I was extremely excited to work on Spanish literature for SAA. This is a new opportunity to be able to help others that have been greatly underserved. One of my missions in life is to be able to help as many people as I can and leave the Earth a better place. Providing literature in the second most spoken language in the world has granted me the privilege to open the door to help those living with AS in countries where little to nothing is known about the disease.

What do you like most about working at SAA?

My colleagues! They are all awesome. Coming into the office (back when we did that) felt like visiting friends. We even know each other's dogs. We all support each other, no task is too big, and everyone is always willing to pitch in. We all have our own strengths and experiences that add to our dynamic team. We may be a small staff of 12 but I am very confident that there is nothing this team cannot achieve. Working remotely hasn't changed that feeling one bit.


Manny's dog, Luna

Name a resource or two that readers should know about.

There are two resources that are vital. The first is our website. There is so much helpful information. I refer to it when I have an unanswered question about SpA. The webinar and seminar section of our website is a wealth of information from leading medical professionals who are on the forefront of treating and researching SpA. The second resource is SAA staff. When you call into SAA or email, you are speaking to a real human being. No phone call or email goes unanswered or unreturned.

As the face of the SAA Development Department, it is Manny's role to be on the frontline – you can always hear the smile in his voice. He has incredible resources and information at his fingertips! Please feel free to reach out any time and get to know him. Also, Manny is the coordinator for the new SAA Community Forums. You can post a question there and connect with other SAA members…and probably Manny as well!


Spondylitis
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of America™

Espondiloartritis
JUVENIL

La espondiloartritis juvenil es responsable de alrededor de un 20% de todos los casos de artritis juvenil, por lo general en hombres jóvenes. Esto a diferencia de la mayoría de otras formas de artritis juvenil (i.e. artritis idiopática juvenil) que comunmente se ve en mujeres jóvenes.

Cuatro de cada 1,000 jóvenes están afectados por la espondiloartritis juvenil, haciéndola una enfermedad inusual. La espondiloartritis juvenil normalmente comienza en los años preadolescentes o adolescentes, generalmente después de la pubertad. Se desconoce aún la causa exacta de esta enfermedad, pero sabemos que los jóvenes que heredan un gen llamado HLA-B27 de uno de sus padres, son más propensos a desarrollar la enfermedad en comparación con otros jóvenes. Sin embargo, ya que el gen HLA-B27 se encuentra en el 8% de los jóvenes caucásicos que nunca desarrollan la enfermedad, ésta no se puede utilizar para establecer un diagnóstico concreto. Es decir, al obtener un resultado positivo hacia el gen HLA-B27, no necesariamente significa haber adquirido la enfermedad. Muchos otros genes y factores pueden llegar a contribuir al diagnóstico de esta enfermedad. A veces los síntomas se desencadenan después de una infección del tracto intestinal o genitourinario. No obstante, hay muchos casos que han demostrado que una infección previa no es necesaria para desencadenar los síntomas.

www.spondylitis.org

¿Cuáles son los síntoma

En jóvenes, la espondiloartritis norma
en una articulación de la pierna com
rodilla, o en la cadera. Puede tomar m
que otras articulaciones sean afectadas,
la columna vertebral o las articulacion
En cada persona la enfermedad se man
manera diferente. Ocasionalmente, el p
que se da a conocer en esta enfermedad,
Un dolor y sensibilidad debido a la inflan
ligamentos y tendones donde se adhieren
este caso, el dolor no está en la articulació
artritis idiopática juvenil), sino que se pro
alrededor de la articulación. En juveniles, l
es más común bajo el talón, detrás del taló
de Aquiles), bajo los dedos de los pies donde
adhieren al pie, o alrededor de la rótula. Alre
20% de pacientes jóvenes que sufren de espo
anquilosante desarrollan inflamación en el o
llamada uveítis (o uveítis anterior aguda) o iri
Cuando esto ocurre dentro del contexto de la
espondilitis anquilosante juvenil, esta puede c
dolor, enrojecimiento del ojo, sensibilidad a la l
pueda que ocurran en uno o ambos ojos al mis
tiempo. Aunque no es muy normal, otras
complicaciones de la espondilitis anquilosante j
como el daño a las válvulas cardíacas pueden lleg
pasar.

5

Manny Caro is instrumental in translating SAA material from English to Spanish.

Dr. Deodhar and his wife, Hem, hiking to Mt. Hood

THE SHIFTING LANDSCAPE OF NUMBERS: WHO HAS SPONDYLOARTHRITIS IN THE U.S.?

A DISCUSSION WITH RHEUMATOLOGIST AND RESEARCHER, ATUL DEODHAR, MD

How many people in the U.S. have spondyloarthritis? One might think this would be a simple task – determining an accurate, real-world number. But, as it turns out, that is far from simple.

We reached out to one of our foremost SpA experts to gain a full understanding of what is known, what is unknown, and the gray areas in between. We can't thank him enough for granting us this enlightening interview! (Conducted just after Dr. Deodhar completed a hike up to a glacier on Mount Hood, in Oregon.)

Let's start with what we *think* we know.

We've been using a figure of roughly 3.2 million as our estimated number of U.S. adults who have spondyloarthritis (ankylosing spondylitis and all related diseases combined). We've based this on a 2007 study by Helmick et al, which suggested that the prevalence of overall SpA in the U.S. is about 1.3% of the U.S. adult population. Hence, doing some math with the 2020 U.S. population numbers, we get to about 3.2 million.

Do you think this is an accurate and real-world realistic number? Or is it just the best we have?

Dr. Deodhar: The Helmick paper is a collection of different papers. It's a review article about the burden of rheumatic diseases in the United States. Helmick and his coauthors looked at various published data about how common are, or the prevalence of, certain rheumatic diseases, including spondyloarthritis.

But that's an older paper and in my opinion the estimates there are under-represented. When this was published, the NHANES study – which we view today as the gold standard – wasn't yet done, so its data wasn't available.

Now the NHANES study looked purely at *axial* spondyloarthritis prevalence, which as you know accounts for about half of the entire spondyloarthritis cases, or even less actually. The study reported that the prevalence of axial spondyloarthritis by itself was about 1%.

So now, if you add only psoriatic arthritis, which is *thought* to also be 1% – so another 3.2 million (by the way, this is a derived number for PsA, and I'll get into that a bit later) you already have 2% of the U.S. population being impacted, and you still haven't captured reactive arthritis, or those with IBD-associated arthritis. So realistically, we're probably looking at a number at minimum roughly around 6.5 million to 7 million. But I don't have a specific study to point you to. It just doesn't exist. There hasn't been a good quality study about the prevalence of total spondyloarthritis in the U.S.

Why do you think that is? Why do we lack a definitive study with clear numbers for all of SpA?

Dr. Deodhar: It's a huge undertaking to do a study of that magnitude, and is very expensive. Someone has to take the initiative to do this population prevalence study, and secure the funding needed. Unless somebody takes the initiative… and SAA could do that. SAA could decide you want to do this study, or go after funding for it. So unless someone takes the initiative, it won't get done.

So the gauntlet has been thrown down by Dr. Deodhar. Get this study done!

Dr. Deodhar: Yes! We should start a massive $10 million fundraising project and then we can do that study.

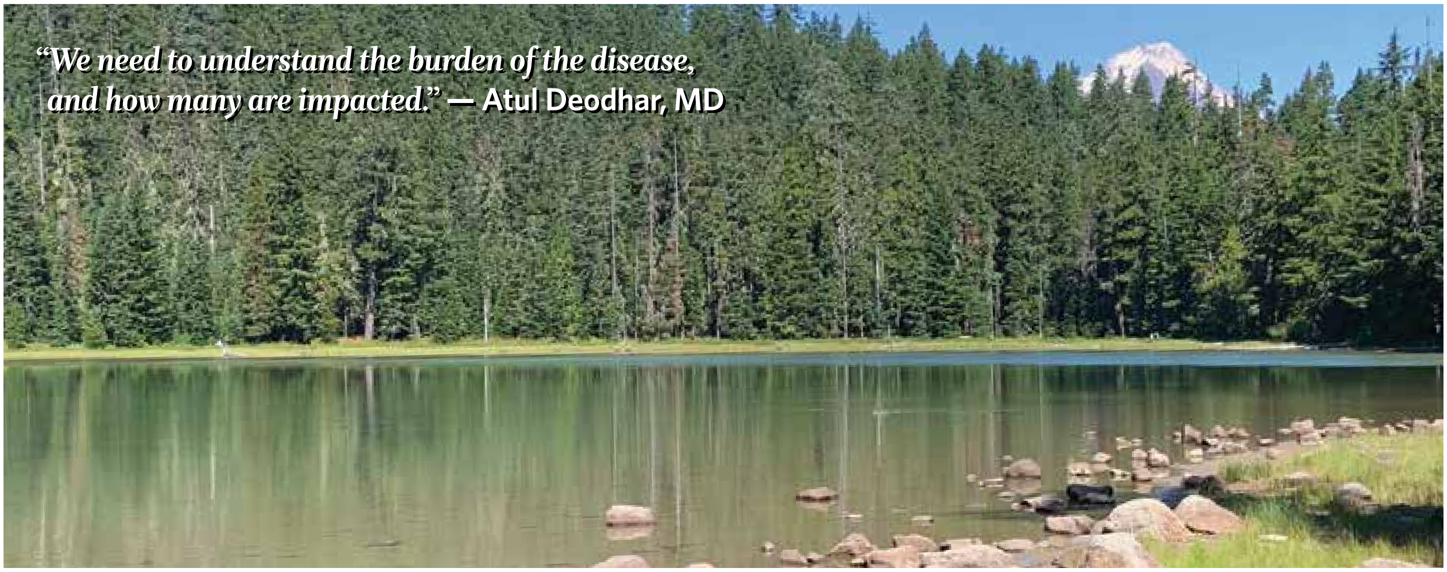
Let me also say there are two ways you can study prevalence. One is determining *population prevalence*, like the NHANES study. This kind of study investigates the general population to find the number of people who have the disease. This kind of study requires a lot of infrastructure, time, resources and a great desire to do it. It is challenging, and a very big undertaking.

The second way of studying prevalence is by looking at *diagnostic prevalence*. Diagnostic prevalence looks at an institution, say UCLA, asking them to provide the number of people they saw in the last year who had the various forms of spondyloarthritis (how many with PsA? With IBD-associated arthritis? With axial spondyloarthritis, etc.) And you add those all up.

And then you ask them to provide the total number of patients they had in that same year. So let's say, just for example you find that out of the 1 million people who came to UCLA Medical School that year, 10,000 of them had one of these conditions. So that's a number of 10,000 out of 1 million.

And finally you extrapolate from that applying that same math to the total U.S. population. But this is *diagnostic* prevalence, which counts only those with SpA who came to UCLA, and were diagnosed with or treated for one of these conditions. This approach excludes people outside walking on the street in Los Angeles who have the disease, but would never go to a doctor because they don't have the resources, or they don't know where to go, or whatever the reason is. Or maybe they went once and were never diagnosed, or misdiagnosed, et cetera, et cetera. In short, diagnostic prevalence is always an underestimation of the real prevalence. The gold standard is a population prevalence study – like the NHANES study.

Your earlier question was why we don't have a solid population prevalence study for all of SpA. Yes, it's very expensive, but also it needs to be planned out very carefully, and many things need to be thought through: What kind of questions will be asked; what kind of examinations we will do, what kind of blood tests do we use, and start building and planning for it, and one day – get to it.


"We need to understand the burden of the disease, and how many are impacted." — Atul Deodhar, MD

Can we also go back and elaborate on the 1% of the U.S. population with psoriatic arthritis figure being a derived number? What does this term signify?

Dr. Deodhar: Yes. Derived number just means that there was no direct study done for psoriatic arthritis prevalence. In this case, the study was done on psoriasis – so a very good, NHANES study was done which showed that the population prevalence of psoriasis in the U.S. is 3.2%.

So that is now a fact. And then another fact is that 30% of those with psoriasis have psoriatic arthritis. Doing some math, 30% of that would be roughly 1% again. We can say that 1% of the U.S. population probably has psoriatic arthritis. That's what it means to be a derived number. It is not from a study. It is a calculated number, so we are less confident with it.

Do you personally think it's important to have a high-quality population prevalence study completed, producing a definitive number for spondyloarthritis prevalence? Why or why not?

Dr. Deodhar: These things are important. Yes, absolutely. We need to understand the burden of the disease, and how many are impacted. The world's governments need to have this information in deciding where to put resources, to plan for the accurate percentage of people with chronic illness, percentage who might become disabled. It's important for public health planning, and for research, and for our patients to know as well.

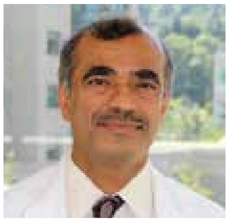
To try and estimate a realistic number, in the absence of a definitive study is difficult, but we do have that 2% figure. Would you feel comfortable in saying that the population prevalence of the entire family of spondyloarthritis is at least 2% of the U.S. population, so at least 6.4 million adults?

Dr. Deodhar: Yes, I'm quite comfortable with that. Though we lack a precise study, I can defend the estimate stating some of the information I've already shared with you.

Thank you so much! Any closing thoughts on all of this?

Dr. Deodhar: I would say that spondyloarthritis has been a stepchild for rheumatologists in the U.S. It has been mostly rheumatoid arthritis, gout, and lupus to get the attention and funding for research, as well as from rheumatologists. Spondyloarthritis is slowly regaining its rightful place in large part because there are newer drugs on the market, and more treatment options coming to market. People are getting interested, and patients themselves as well as organizations like SAA are actively pushing for awareness and recognition.

The classification criteria has opened eyes about axial spondyloarthritis. New terminology and an ICD-10 code has come in: Non-radiographic axial spondyloarthritis – we didn't even know about this term. We knew the existence of the condition and we called it generally undifferentiated spondyloarthritis. But now people are becoming aware of this condition as well. So my parting words: I believe that people are gaining interest in spondyloarthritis and once they start taking interest, then the type of study that you're looking for – researching the true population prevalence of all of SpA – is more likely.



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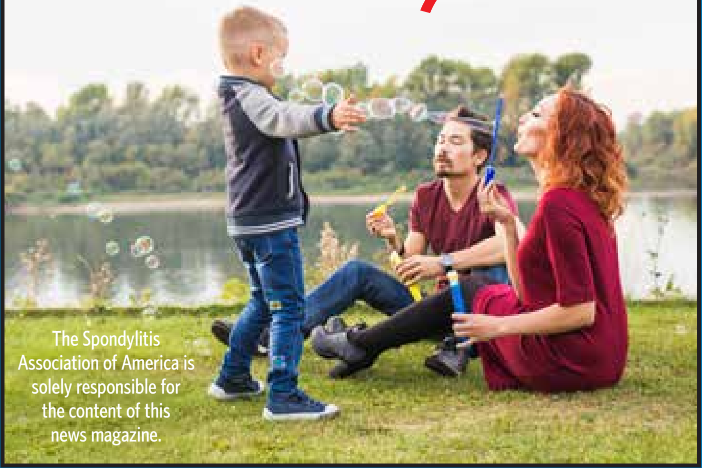

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HOW TO GET MOVING WHILE STAYING HOME

For many of us, the ongoing pandemic has turned our sense of routine on its head. As a result, we may not be as active as we used to be. Yet studies continue to show that exercise is one of the most beneficial lifestyle treatments for spondyloarthritis (SpA). Regular exercise has been proven to optimize physical and mental health, and counteract some of the impacts of SpA. We spoke with physical therapist Tami Grunitzky, DPT on incorporating more movement and exercise into our days even if staying home.

Read on for a wealth of suggestions and tips, then be sure to find her, and other fitness professionals in our updated exercise series, *Back in Action, Again*, as they lead you through safe and effective movements. Find the exercise series on our website at **spondylitis.org/back-in-action-again**.

We know that exercise is a big part of your life. Have you managed to maintain your regular level of activity during the pandemic? What has changed in terms of how you exercise and how you've adapted to keep active?

Tami: When we were in full quarantine shutdown and the gyms weren't open, my gym allowed members to take equipment home and utilize it at our houses. And they offered Zoom classes we could attend, or they would record classes and we could watch them later. So I had some weights and a barbell and a dumbbell, and I just followed the programming that my gym did daily and tried my best to attend a Zoom class when I could. When I couldn't, I worked out by myself in the basement, or if it was nice enough, I'd take things outside and get some fresh air. I also took my daughters for hikes and we tried to stay active that way – hiking and exploring different areas. I tried to make the best of what we had available and tried to keep moving and doing something every day. Even if it was just taking the dog for a walk one day, we did something.

That's great. How can we all incorporate more movement into our days? Especially now that many of us are staying home more and doing a lot more sitting, we may be more sedentary than usual. Can you share some specific recommendations for quick stretches or exercises we can do in small bursts and in smaller spaces throughout the day?

Tami: When you're staying home, walking is a good option – just getting outside and getting some fresh air every day, if you can. You can do small exercises indoors, as well. It can be as easy as using a chair to stand up and sit down from little mini squats. You can do standing exercises at your countertop, such as calf raises. You can do assisted squats and lunges using your countertops, too. If you have stairs in your home, make a few extra trips up and down the stairs. As far as some quick stretches, if you're able to get down on the floor, you can lie on your back, bring your knees into your chest and hold them there. You can also cross one knee across your body and get a good stretch in your buttocks and in your glutes.

You can do some chair stretches. We are sitting a lot more; many people are working from home and on a computer, and our shoulders get really rounded forward. That breeds a lot of back pain and shoulder and neck pain. So just try sitting at your chair and putting your hands behind your head, and arching your back backwards to open up the front of your body. You can do this over the back of your chair, or if you have a foam roller at home, you can stick the foam roller across your back and arch over that and use it to deepen the stretch.

Don't forget that so many common things we do throughout the day count as exercise and can help improve function. Getting down to pick a child or small pet up off the floor is a squat and lift. Going up and down the stairs is a great leg exercise. Carrying grocery bags requires arm strength and some balance and core strength. The more fit you are, the easier these tasks become.

What kinds of exercise do you generally recommend for those with SpA?

Tami: We often talk about strength exercises, cardio, flexibility, and range of motion as important, and that's no different for those with SpA.

Strength training is wonderful because it helps increase bone density and also strengthens your muscles, and keeps your core nice and strong. If you have weights at home and you feel comfortable using them, you can use small dumbbells or a small barbell to add resistance to squats or lunges. You can do bicep curls. You can do standing calf raises. You can do bent over rolls for your upper back muscles.

Tami Grunitzky, DPT

As far as cardiovascular exercise, get outside and take that walk. If you have access to a pool, the pool is a wonderful place, especially for those with SpA because it allows for more freedom of movement without the achy joint pain that is sometimes experienced with higher-impact exercise.

You can also try yoga. There are a lot of tutorials on YouTube, and different virtual platforms offering yoga classes. You can search for gentle yoga and do what your body feels comfortable with. If you come across a pose that you know your body wouldn't get into, then don't. You have to listen to your body and do what fits your needs. But the stretching and the flexibility that you get from yoga are excellent. Tai chi, too, is great for balance and general movement and core strength.

If you do belong to a gym and don't feel comfortable going there, a lot of gyms are offering Zoom classes. They're streaming their group exercise classes so you can do them from home.

Regarding these different kinds of exercises, how much would you recommend? How should someone start who's new to exercising, or who may not have been active for a while?

Tami: You want to start slowly. I think 10 minutes is a great goal. If you can go out and take a 10-minute walk or do 10 minutes of movement in your home, see how your body responds to that. If that feels good, then gradually add minutes until you've built yourself up to about 30 to 45 minutes. But that's not where you start. Just getting up and moving, getting some blood flow circulating through your body, and getting your muscles pumping is the goal.

That sounds so unintimidating and so doable!

Tami: Yes! You just work yourself into it. People think, "Oh my gosh, I can't start that exercise class because it's too much and I'll never make it through." You don't have to. Especially now. You're in the comfort of your own home and there's no one around to judge you. So when you turn off that screen, congratulate yourself instead. Do what you can and slowly build up to do more if that's your goal.

Can we talk about some recommendations for exercising safely, and any modifications that might be necessary or helpful for those with SpA?

Tami: I would say that balance is especially an issue, and you should have something sturdy by you at all times when you're doing any of your standing activities – like a countertop, a heavy chair, or the back of the couch – something that will support you if you feel the need to grab hold of it. Second, you don't want to overwork yourself. If you're having a really great day and you're feeling good, don't try to push way beyond your means just because you feel strong at that moment. You might up the intensity when you're feeling well, but take it half a step higher than what you're used to and assess your body after that. Then you can progress further from there.

You also want to think about using good body mechanics when you're doing any of your movements. That means your core is braced, your chest is up and tall, and you can breathe easily while you're doing the movements. You'll also be using your legs, which are much stronger than the muscles in your back, especially if you're squatting or lunging.

So be aware of using good posture and good body mechanics while you're exercising. You also want to make sure you're breathing! Make sure you're taking nice big belly breaths and keeping your heart rate at a reasonable level.

Are there any exercise props or products you would recommend, that would be helpful for those with SpA?

Tami: Yes. I mentioned the foam roller earlier – I think that is a great prop to use to help you stretch and mobilize and work out some muscles that might feel a little sore and stiff. You can do gentle rotational exercises, to keep yourself as mobile as possible. Small hand weights might be helpful if you feel comfortable with adding some resistance. Resistance bands are also fairly inexpensive and easy to come by. A chair is actually a great prop! You can use a chair to help you squat or lunge, to do triceps dips and modified pushups. Having a sturdy chair nearby is really helpful.

Thank you, Tami! Do you have any closing thoughts for our readers?

Tami: I think the main takeaway is to just get up and get moving. Try not to get into that familiar rut. Start to build a routine that you can get into and maintain. Start small and gradual. You won't mind doing just a few minutes of exercise each day. It's so important for circulation throughout the body and maintaining your mobility. And even though you might have to get used to moving more, do little bits at a time, and your response will improve. Doing this will help keep your body functioning as it needs to.

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THE TRICKY (AND LONG) ROAD TO DIAGNOSIS

by Shane Derbyshire

Hi, my name is Shane Derbyshire. I am a chiropractor from Norwich (in the UK) and I was diagnosed with axial spondyloarthritis (axSpA) in 2018. I would like to share my own experience as a chiropractor with this condition and my journey to getting a diagnosis.

The Start to My Journey

In 2017, I started to get a lower back ache that seemed to be made worse by sitting still and was a kind of back pain that I had never experienced.

Exercise and movement seemed to improve things, but no matter what I did – the pain persisted!

It should be kept in mind that I am a chiropractor, so it was starting to prove quite frustrating that I couldn't shift the pain.

Something wasn't right.

I was quite stressed at the time as I was starting my own business and had also moved into the city. There was a lot of upheaval in my life. I put my lower back pain down to stress and thought that it would eventually pass.

But fast forward a few months, and symptoms began to progress.

A Pain In the Eye

I woke up one morning and I thought I had something in my eye. It was painful when my eyes focused on nearby objects and when I looked at anything bright.

I looked in the mirror and one eye was bloodshot. Very odd!

My clinical mind started to kick in.

The symptoms lined up with something I had studied before. "This might be uveitis!"

A few moments passed.

"Oh no! I think I might have ankylosing spondylitis!"

It began to sink in that there may be a connection between these symptoms that I had not been able to explain before. I started to recap what I had learned at university and I ensured that I knew what the right protocol was to get a diagnosis.

Knowledge is Power

I went to my ophthalmologist appointment knowing that I may have this condition so I could find out how I would be managed after this visit. And that is exactly what I did.

I ensured that they were aware that I had lower back pain (which was unusual for me) and I also ensured that I was being sent for further tests to rule out the underlying cause of my uveitis.

Many people don't have the luxury of the background knowledge I had, and can become lost in the system and have to wait many, many years until they are diagnosed. I know I was very fortunate in this regard.

The ophthalmologist and I discussed the possibility that the symptom in my eye could be a manifestation of another underlying condition – axSpA.

Diagnosis Tip - Ask clinicians if there might be any underlying reason for your unexplained symptoms.

The First Major Step Forward

Once I was diagnosed with uveitis and after a difficult conversation with the ophthalmologist, I was sent for further tests.

The test for the HLA-B27 gene was ordered, because many people who have axSpA also have this gene.

It came back positive. Brilliant! One step closer to a diagnosis.

Once I had a test result that said I was HLA-B27 positive, this opened up a lot of other possibilities.

Diagnosis Tip – Ask for an HLA-B27 gene test to see if you have a genetic predisposition to this condition.

Editor's Note: HLA-B27 is a normal gene found in about 8% of the Caucasian population. Generally speaking, no more than 2% of people born with this gene will eventually develop ankylosing spondylitis. The association between AS and HLA-B27 varies among different ethnic and racial groups. It can be a very strong indicator for some, in that more than 95% of people in the Caucasian population who have AS test positive for HLA-B27. However, close to 80% of AS patients from Mediterranean countries, and only 50% of African American patients with AS are HLA-B27 positive.

Other bloodwork that can at times be helpful includes the erythrocyte sedimentation rate (ESR) test, also known as SED rate test, and C-reactive protein (CRP) test. These tests check for markers of elevated inflammation, which may indicate systemic arthritis, among other things. We'd like to note that not everyone with AS will have elevated inflammatory markers, nor test positive for the HLA-B27 gene.

The Confirmation

Now that I had a history of uveitis and a positive result for HLA-B27, I was then referred to a rheumatologist.

He recommended a specific "T1 weighted" MRI that can be used to detect inflammation within the spine.

The results came back positive for inflammation in the sacroiliac joints and indicative of axial spondyloarthritis.

There it is. In writing. The explanation to my 18 months of symptoms.

It comes as a relief, but also as a blow. It is now confirmed that I have a chronic illness.

But now at least I can get the right help, and have a good chance of positive outcomes with this disease. And this is why early diagnosis is so important. Without the right diagnosis, we will not get the right help.

Diagnosis Tip - Ask for an MRI to detect the presence of S.I. joint inflammation.

In Conclusion

So that is my experience in getting a diagnosis. I have been one of the fortunate ones who got a speedy diagnosis. I know that this journey is often wrought with potential missed opportunities and oversights, which can lead to long delays. My hope is that we will all move toward the day when a speedy diagnosis of axial spondyloarthritis is the norm everywhere.

Thank you for reading!

Shane Derbyshire is a GCC registered Norwich Chiropractor that has been practicing Chiropractic in Norfolk, UK since 2015.

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