

Melissa Velez Coelho: Welcome to this month's podcast. I'm Melissa Velez Coelho, Director of Program Services at SAA and I'll serve as your host for this podcast. Today it is my pleasure to interview Dr. David Hallegua. Dr. Hallegua is a rheumatologist specializing in Clinical Research, Patient Care and Teaching in Los Angeles, California. He is affiliated with Cedar Sinai Medical Center and is an Assistant Clinical Professor for the David Geffen School of Medicine at UCLA. Dr. Hallegua is a member of SAA's Board of Directors and is outgoing Chair after serving as Board Chair for the past four years.

Today we're going to answer some questions asked on our message boards. You can find details on where to send your questions on the member podcast page. Your question could be answered on an upcoming podcast. So let's get started. Welcome to the podcast, Dr. Hallegua.

David Hallegua: Thank you, Melissa. What can I answer for you today?

Melissa Velez Coelho: Okay. The first question we have has to deal with diagnosis. Cherie writes: I would like to know if the experts have any advice on getting diagnosed, what information is the most important to try to pay attention to? I find there is so much going on in my body that I do not know what is important for symptoms. It is a thin line between paying too much attention and ignoring the pain.

David Hallegua: Well, Cherie, this question is a good one and I often hear this asked at presentations. The symptoms that are most important to pay attention to are stiffness that occurs in the morning and gets better as the day goes along. Another symptom that's important to pay attention to is nighttime pain; pain that occurs at night that makes it difficult for the person to stay in bed and forces them often to get out of their beds and walk around, particularly, the second half of the night, namely between midnight and early morning.

The other symptom that you should pay attention to and report to your doctor is the presence in the past or during the period of evaluation of redness of the eyes or swollen joints. This could be an entire finger or toe or swollen joint like a knee. All these constellation of symptoms can be put together by a very competent rheumatologist and come up with enough criteria for the rheumatologist to pursue sophisticated testing with MRIs that will focus on the area that's involved.

If mainly the lower back, in a person with low back pain and stiffness or possibly in the thoracic spine, in the spine that's in the chest area is that's where the symptoms are. It's also important for you to poll your family members and find out if any of them have been diagnosed with either ankylosing spondylitis or a related disease like psoriatic arthritis or Crohn's disease or reactive arthritis since that will also help your astute rheumatologist to give weight to your other symptoms and to reach a diagnosis.

Melissa Velez Coelho: Great. Thank you. This is a question we get quite often. It has to do with women. Why is it so difficult for women to receive a diagnosis of AS and what needs to change so women are diagnosed sooner and receive appropriate treatment options? It's a very common question we get here at SAA.

David Hallegua: Sure, sure. I do agree with you that it is more difficult for women to receive a diagnosis of ankylosing spondylitis. That said, I think it's difficult for a man to receive a diagnosis for ankylosing spondylitis, as well. But, the fact remains that there is probably still a bias, though it is decreasing, that ankylosing spondylitis is a disease that happens much, much, much more often in men than in women and this is probably very wrong.

Most people believe the ratio of men to women being affected with ankylosing spondylitis is somewhere around two to one or three to one, so for ever three or two men, there's one woman affected. Other people feel that if you really uncover all the women who have varied forms of the disease, that it may even be a one to one ratio. The problem remains that women present in a different manner compared to men who present in their traditional manner with low back pain and stiffness, buttock pain that alternates from side to side and often other associated features that I have mentioned early on, symptoms with either nighttime pain or swelling of the joints, etcetera.

Women present with more subtle features like chest pain or chest wall pain in the front or pain in the back in the thoracic area. These are unusual areas for pain early on for ankylosing spondylitis and therefore most physicians, including rheumatologists, do not pick up on the fact that this could be inflammatory spinal arthritis or early ankylosing spondylitis. Women also tend to have pain in their lower back associated with their menstrual cycle and often back pain that may be early AS, could be confused with the regular pain that they might get during their periods or to have as a result of childbirth or carrying a pregnancy that was difficult.

So, all these factors put together makes it more difficult for women to receive a diagnosis of AS. I think that as we come up with better diagnostic testing and criteria, women will probably be diagnosed very equally just as well as men are. These diagnostic criteria include the genetic testing that is coming out that could be used to perhaps pick up a person with the right genes and that along with the right symptoms would reach a diagnosis much earlier. Targeted testing with MRIs in the thoracic spine or the chest wall area can also lead to the diagnosis of early inflammatory arthritis of the spine in a woman who has her symptoms begin in this area. Next question, Melissa?

Melissa Velez Coelho: The next one has to do with pain. Again, a lot of these questions that we're answering today are common questions that we get. Elaine from New Hampshire writes: Pain seems to be under treated. How do we AS'ers get adequate pain relief without looking like drug seekers? What's the best way to approach our physicians?

David Hallegua: Well, Elaine, pain is a very important symptom and is often called the fifth vital sign in the hospital setting. So, I think that somebody, a physician is not paying attention to the treatment of pain, then its time to look elsewhere. Anti-inflammatory medications are the No. 1 medicines that are used in treating ankylosing spondylitis patients who have pain and they seem to be adequate in treating pain in about 50 percent of AS patients.

However, in the remaining 50 percent do not get adequate pain relief with this group of medications and by 'anti-inflammatory' medicines, I'm referring to the ones that are present that are available over the counter such as ibuprofen, naproxen, and other prescription medicines like indomethacin, Celebrex, etcetera. The remaining 50 percent who were not relieved by this group of medicines needs more aggressive treatment.

Now, I would venture to believe that at least 75 percent of the people remaining from that half could get significant relief with the Tumor-Necrosis blocker medications and these are the Enbrel, the Remicade and Humira – a group of drugs that are injectable medicines, either self-injectable or infused, that have shown a remarkable ability to decrease pain and improve function with ankylosing spondylitis patients who have either limited joint mobility and pain or even full fusion and pain. Those patients appear to get relief from these drugs, as well.

There's probably a remaining 10 or 20 percent of patients who have advanced deformities where their spine is totally fused and bend forward that do not have adequate pain relief even with these drugs. They have a lot of mechanical problems and they need treatment for pain with the pain pills such as the narcotics that are used to create different kinds of pain, but including cancer pain. You gotta find a sympathetic rheumatologist who is comfortable prescribing these drugs or go to a specialist called a pain management specialist who can assess pain on a regular basis and titrate the medications to give you pain relief without giving you too many of the side affects.

Melissa Velez Coelho: Let's move on to a disease progression. Raquel writes: How often should we, if at all, have scans to see if the AS has progressed and damaged to the areas that are affected by the AS, what kind of scans should be done?

David Hallegua: Well Raquel, you sound like a patient that's already been diagnosed and perhaps worried about whether your AS is the kind of AS that might progress and cause damage and more fusion and limit your range of motion. Well, there are a number of things that can be done besides scans to look and see if AS is progressing or not. The simplest thing to do is something called metrology indices.

Metrology refers to measurement and these measurements are done in the physician's office, usually a rheumatologist who is used to seeing patients with AS will know about that. The test involved includes a test where there is lateral bending of the spine and this lateral bending of the spine will get more limited as the disease progresses. In general, people are able to bend laterally and have the measurement be more than 15.

When the lateral bending gets to be less than 10, then we start talking about mobilization with range of motion. There are other tests that can be done. These include X-rays and MRIs. X-rays, when they are done to look and see if there are changes occurring due to ankylosing spondylitis, should probably be done once a year and changes that the rheumatologist and radiologist look for are squaring or square shape to the vertebrae that are usually by concave in shape, as well as the ligament calcification that we commonly see with ankylosing spondylitis as its progressing.

MRIs are sensitive to change, as well and MRIs could show inflammation in new areas of the spine or of a particular joint or bone, such as the heel, which has suddenly become more painful

and thus indicates that the ankylosing spondylitis in a given patient is more active.

Melissa Velez Coelho: So if they are able to determine that there's a lot of progressed damage, what should be done? When does surgery become an option?

David Hallegua: Surgery becomes an option when you have a significant change in your posture or when a joint such as a hip joint gets to be fused or very painful to walk on or where you are unable to walk from your bedroom to the bathroom or from a car into a store. That would be the point that most people consider surgery for. If you do surgery earlier, you are often not satisfied with the results. The surgery that is particularly successful in ankylosing spondylitis patient is surgery on their hip, where a hip joint is replaced when this joint wears off.

The surgery at the spine is often on people who have advanced disease and are stooped over where they are not able to walk with their spine straight anymore and this type of patient can benefit from a surgery that's often done in a couple of stages, first correcting a deformity either in the neck area or the thoracic area or the lumbar area, depending on which area is affected the most. This is generally done with a procedure called an osteotomy where a wedge of the vertebrae is removed so that the spine can be straightened back where the patient has a better stance and walk and is able to look straight ahead while they walk because their posture is improved.

Melissa Velez Coelho: This question is about TNFs and again, it's a common question that we get: Which TNF has the best safety record and the most success rate? How long should you stay on the medication before it's decided that it does not work or you need to add in a DMARD before stopping or changing the medication?

David Hallegua: Well there are three Tumor-Necrosis Factor blocking drugs that are approved. Enbrel was the first one to be approved followed by Remicade, which is an intravenous medication and Humira. It's important to know that there are no head to head studies meaning studies that compare Enbrel to Humira or Humira to Remicade, etcetera, to really answer the question as to which one has the best safety record or the best success rate.

When you look at studies that have led to the approval of these drugs, they're all effective. They defer in their route of administration, how fast they work and whether they work for

certain associated conditions that can occur with ankylosing spondylitis. So, if one looks at a patient who has psoriasis or Crohn's disease associated with ankylosing spondylitis, then the choice should be either Humira or Remicade because these drugs do work for those conditions very well and probably should be preferred over Enbrel.

On the other hand, if you have a patient who perhaps does not like to go to the doctor's office and get an infusion performed every six to eight weeks and wants more control over administering their medicines themselves, then the Enbrel or Humira, which are self injectable medicines given once a week or every two weeks, in the case of Humira, should be the choice. In terms of as a safety record, these drugs are being examined long term to see what would be the safest way to go. So far, they are very safe medications in that we do not see the common peptic ulcer disease and bleeding from the stomach as we have seen with the anti-inflammatory medicines.

We do not see elevated blood pressures or fluid retention, with leg swelling that we saw with anti-inflammatory medicines or with liver toxicity that we saw with methotrexate or bone marrow toxicity that we saw with sulfasalazine that was used to treat ankylosing spondylitis in the past. The concerns with these drugs are that because they suppress the immune system that infections can emerge. And what we worry about more than the colds and the coughs that we all get are opportunistic infections, meaning infections that perhaps one has been exposed to in the past that would resurface because the immune system was suppressed. An example of this is tuberculosis.

So, if you had exposure to tuberculosis, which is a disease of the lungs, you could harbor some tuberculosis bacteria within an area of the lung for many years, 20 to 30 years. And when these medications are used, the immune system is suppressed where those tuberculosis bacterial that are lingering in the body can finally become active and multiply and give you active tuberculosis. With respect to that side affect, the drug Enbrel seems to have the best track record in terms of having the least number of tuberculosis cases that have emerged in treating patients with ankylosing spondylitis or rheumatoid arthritis.

The other two drugs have more cases that have occurred with them, but again, we are not talking about huge numbers of cases. We are talking about very small numbers and most people, when treated appropriately with skin testing for tuberculosis, you can

readily treat ahead of time for this complication and totally prevent it. I think you need to give about at least 12 weeks to see if a medication is working before you stop it and you do not need to add a different medication before you stop or change the medicine.

You can stop the drug and switch to another medication if you are going from one Tumor-Necrosis Factor blocking drug to another one. So, these are very great advances and we are happy to have these drugs to use in our patients that fairly need it. We do believe that time will tell us that whether these drugs are truly disease modifying. Whether they prevent fusion or not, we are able to answer that question yet because we have not treated patients that have very early disease with these drugs and all of them long enough to see if fusion can be prevented.

Melissa Velez Coelho: Alright. Well thank you so much for your time today, Dr. Hallegua. We really appreciate it.

David Hallegua: Thank you, Melissa.

Melissa Velez Coelho: This concludes this month's podcast. Be sure to check back each month for a new podcast in the member area at spondylitis.org. Until next time, thanks for listening. Thank you again, Dr. Hallegua.

David Hallegua: My pleasure. Alright, take care.

Melissa Velez Coelho: Thanks, bye-bye.

David Hallegua: Bye.

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