Sjögren Syndrome: The Overlooked Autoimmune Disease Affecting Millions Transcript

(Transcripts are generated by AI and may contain errors)

Introduction and Kara Wadau2019s background

Welcome to another interview for the M. S. and Autoimmune Summit. I'm doctor Terry Wahls your host in the personal interview. Next is Doctor Kara Wada, a four times board certified assistant professor and physician who specializes in allergy immunology and most importantly, lifestyle medicine and autoimmune patient advocacy.

So she's a, physician after my heart. And, Doctor Wada, when you say four times board certified, what are the four boards that you're certified in? So my residency was in both internal medicine and pediatrics and then allergy immunology.

And then I sat for the lifestyle medicine boards in 2021. And I am hard at work and finishing up my functional medicine certification as well. This is excellent.

So this really gives Doctor Wada a unique perspective. I love that she's certified in pediatrics and internal medicine because these autoimmune diseases affect our children as well as adults, and children are being affected at early and earlier ages.

But when I talk about Sugarfoot, I'm not sure many of our audience members will have heard of sugar. And so let's first define what that is and why people who may have some brain symptoms, that children's would be part of the differential.

Yeah. So showgrounds is one of the most common but least known diagnoses in the autoimmune sphere. It is a condition that can affect us from head to toe.

And as clinicians, what we've learned through our our training often is its association with tissue dryness, which can cause dry eyes and dry mouth for goodness.

It is so much more than those multiple choice test questions. And it really was my own diagnosis with Showgrounds in 2019 that really opened my eyes to the the breadth of symptoms.

So, it often is associated with neurologic symptoms, as you mentioned.

What Sju00f6grenu2019s is and why itu2019s missed

And that can span anything from small fiber neuropathy which can cause numbness, tingling, burning sensation, often in the hands and the feet, but really anywhere across the body.

It's also the number one autoimmune cause of something called this autonomia. So this umbrella term that also encompasses things like pots such as postural orthostatic tachycardia syndrome.

So when you change position, your heart may raise you may have a tendency to have your blood pressure drop or pass out even. And in some cases it can mimic symptoms of Ms..

So when folks are being evaluated for issues related to neuropathies pain you know, pain syndromes, other things, this is something that should come up on that list of diagnostic possibilities.

But unfortunately, that association with the nervous system involvement is not really stressed in medical education. So sometimes it gets left off the list.

Yeah. It, it's my understanding. And please correct me if I'm, not correct here, that I don't believe there are any FDA approved treatments for sure. Absolutely correct. We're on on the brink.

So there are, about five medications that are in late stage clinical trials. But yeah, up until the point where we're recording this, there is nothing approved.

And and frankly, that is what that was one of those turning points on with my own diagnosis. I picked up your book. You know, I got interested in lifestyle medicine and and in part because the treatments that we had available and in my more typical medical toolbox weren't sufficient.

Yes, yes. So it's so important for anyone with an autoimmune disease to be, if you're so fortunate you have FDA approved drugs, you know, fine. I think that's terrific to use them. Yeah.

But another critical part is this lifestyle medicine. So why don't we talk a little bit about, you know, your journey and the lifestyle interventions that you were using?

Yeah. So, I think first and foremost, letting go of perfection was one lesson I had to learn real hard, real quickly. And and part of that was, you know, a life of really always trying to aim for that next gold star.

Very Type-A, you know, personality is 1st May not be super surprised with a career in medicine. But I think really reevaluating how I respond to stress and, learning different tools for nervous system regulation have been really critical.

I think the other is helping, repair gut health. So, you know, thinking about all those different ways to remove what's a problem or replace what's missing a re inoculate, the microbiome, repair the lining, and then, and rebalance.

So nutrition has been really key. And one of the biggest levers for me, kind of those top three is sleep. I've really had to commit to, not only aiming for good of sleep, but also, quality, which is not always perfect.

I have three kiddos at home. The oldest is ten, and so, you know, there has to be support from from my, my partner and my my husband and, you know, really trying to make time and space for that rest and recovery.

Now, why? So I think, showgrounds is far more common than multiple sclerosis. Why something that is so common often not. Mr.. You know, often missed in that considered in the differential.

Yeah. So a few reasons. We estimate the prevalence is somewhere between about one and 85 to 1 in 100 people. So again, it is very, a lot more common than one would expect.

I do wonder if a little bit of it is a branding issue. The name is not spelled how it sounds, and it looks when it's spelled out a bit like a name of a chair at Ikea.

So I think that might be a little bit of it. The other, I think, is this preoccupation with dryness. That is what almost all of the medical education leads with.

Lifestyle medicine and personal management

And that is not what patients present with when they go to see their primary care doctor or they go to see a rheumatologist. What they really are sharing with their care team are that they are profoundly fatigued.

Many suffer from a lot of body pain, which looks and feels all the world like fibromyalgia and 30 to 40% of folks who have shoguns disease have normal bloodwork.

So they're considered sero negative. So again, when we think about how how physicians are trained, how clinicians are trained, we often are trained on these very testable aspects of care, which are the dryness.

And then a particular set of antibodies are autoantibodies called SSR and SSP. And those are normal or negative in 30 to 40% of folks. That's a lot of people.

That's a whole lot of people. So the symptoms that are related to shogren. So I want to be sure I have captured that. So we have dryness, dry eyes, dry mouth, dry vagina.

That can be uncomfortable in fatigue. And then this pain sort of diffuse pain that if they were in my primary care clinic, I might be thinking, well, this is fibromyalgia. Yes, but maybe it should be.

So I'll check the showgrounds. Antibodies are negative. So yep, this is fibromyalgia. And I'm trying to help them with pain. How do I ultimately realize I made a mistake?

It's short. I think that's a great question. So one thing that I think often gets missed, kind of our our diagnostic toolbox that we can consider. There are some additional labs that are not part of.

So part of what gets a little challenging is there is a particular set of criteria called the classification criteria, which is a really great list of checkboxes for folks that you want to include in a clinical trial.

But we those checkboxes are not not supposed to be used strictly for diagnosis. Diagnosis is supposed to be more clinical. So I think that's one distinction that often kind of gets muddy.

So there are some other diagnostics that I found helpful. One is something called an early shogren profile. It looks at, three different proteins that the immune system can create an auto immune response.

And they're proteins that are responsible for making saliva and tears. So that is a lab that, physician or other clinician can order. So that's another like little less invasive, modality, the gold standard for evaluation is something called a minor salivary gland biopsy.

It's a fancy way of saying a little lip biopsy. It does require a little bit of numbing. It does require a couple stitches, usually done in an oral medicine or an ear, nose and throat office.

Rarely, a rheumatologist will do that.

Why Sju00f6grenu2019s is often overlooked

And one other modality that I am very interested in and excited to get trained in later this spring is actually ultrasound of the cell very gland. There's some classics signs you can see in that black and white that look for inflammation there.

I think what's hard though is that all of those modalities are focused in, again, on the dryness. And for some folks, the dryness comes later in the disease course.

So I think, you know, going back to your question, if you're seeing someone and you're like, okay, well maybe this is fibro, but kasha, it just seems more like this person is really fatigued.

They're not able to play with their kids or their grandkids. They're having trouble with work. Brain fog is really challenging. We've ruled out some in these other conditions.

I think that's when you start asking like, is this really is this, you know, is that it? Is there something more if they're experiencing joint stiffness, arthritis also can go along with sugar things which you would not necessarily expect with fibromyalgia.

Thankfully that arthritis tends not to destroy them, the joints. And one other thing I would think about is if someone is having issues with breathing a dry cough that's persistent, or shortness of breath, a percentage of patients with children's will have, development of something called interstitial lung disease, which, is something that needs, you

know, you don't want to miss, because that can really impact, long term health and longevity, too.

You know, if someone comes in to see me, you know, with, with fatigue, plus minus dryness, some neurologic symptoms, and I'm now sensitized. I'm thinking, okay, should I be thinking about children's?

But what happens if if it's delayed? Because, you know, many, many people with autoimmune diseases, we have symptoms for years. The initial lab work is negative.

I'm feeling gradually more fatigued, gradually a little more foggy in my thinking, a little more pain. How long can this symptoms be before a diagnosis?

You know for sure. Good is finally made. And what happens with that delay? Yeah, so we see the average is somewhere between 2 to 6 years depending on the study you look at.

And that's the average. I look back at my own story and I now see symptoms that I had the summer before I went to medical school. So around 21 or so that I now can kind of connect the dots.

So that was a good ten plus years before I was diagnosed. So super common. I think, you know, things I think about one of the things that's most scary for folks after they receive a diagnosis of showgrounds and they go looking for more information, is that there is about a 10% lifetime risk in some studies of development of lymphoma.

Now, what you if you keep reading, we'll find out is that thankfully that lymphoma often is slow growing and also doesn't tend to shorten someone's lifespan.

But goodness, if you tell someone off the bat that they have a 10% lifetime risk of cancer, that's pretty scary and doesn't feel good. And so I think that that's one thing that I think is really important to get the diagnosis right, because if you have a population that has an increased risk of something, you want to be more thoughtful.

If they have blooms or bumps or having more night sweats, are other things you want to be more thoughtful about evaluating that in a higher risk group of folks.

Diagnosing Sju00f6grenu2019s and related symptoms

The other thing that I think is really important to think about is when we have unchecked inflammation that has ongoing impact on our cardiovascular system.

So we know folks who have chronic inflammatory diseases. Autoimmune diseases are at higher risk of heart attack, higher risk of stroke. And those are, you know, those are risks that goodness, if we know, are at higher risk, at least for me, that's been very motivating.

When I think about using lifestyle as medicine, because a really good data to say that working out, you know, getting some exercise in eating, you know, all of, fruits and veggies and lots of fiber, those different things are all really helpful at bringing that risk back down again for the listeners.

I want to, reiterate that whatever systemic autoimmune disease you have, our innate immune system is more active and we have higher rates of heart disease.

We have higher rates of stroke then compared to the population who does not have an autoimmune disease. Now, what about a sidebar here for a while, because many of the listeners are women.

What I was trained and probably what you were trained, doctor Wada was on the symptoms that men have when they have heart disease and, you know, or heart attacks.

And they weren't we were not trained at all as to what women have. So, doctor, what are you going to tell our audience? The cardiovascular symptoms that men have in the cardiovascular symptoms that women have, but

how?

We're a little bit different if we're having, you know, for men it is more of that typical, you know, grab your chest pressure elephant on the chest pain for women, it often is more subtle.

It can feel like really bad indigestion. And and this gosh, this strikes home for so many reasons. One, my grandmother, when I was the senior in high school, she missed her initial heart attack and she unfortunately had, you know, a secondary heart attack later that same week which resulted in hospitalization.

But, and sadly, that resulted in her passing away several weeks later. I also happen to have met my husband in medical school. He's a cardiologist. So these are some of the conversations we have at home to.

Okay. Which is great. And I think, you know, he is very fortunate that he has had some great mentorship and and learning kind of these, these subtle differences.

But you're right. They're not they're not taught we're not taught that fatigue. You know, we're seeing fatigue can be a sign of, cardiac problem, that indigestion and discomfort can be a sign of cardiac problems.

And then unfortunately, when we go to the emergency room, you know, men, there's a much higher incidence of this might be a heart attack in men than in women.

So be sure and advocate for yourself. Yes. The lenses are different. Yeah. Yeah. It's very very, very troubling. So again, at sort of a higher level, showgrounds.

How many million. So there are about a million people with M. S in the U. S we yeah, 4 million. So four times as common. And there are they have neurologic symptoms.

Do assurance folks I know M. S. has a much higher rate of anxiety and depression and mental health issues. Is that the same with shoguns? Yeah. And actually there's some interesting data.

So my my other half of my life is an allergist. And there's similar data within severe even allergic rhinitis that we see increased rates of anxiety and depression.

And I find it very fascinating, you know, going back to the innate immune system, cytokines, ways that our body's communicating between the immune system and the nervous system.

These chemical messengers have impact on how our brain functions. Yes. And I think we can, correct me if I'm wrong. If you have a systemic autoimmune disease, whether it's showgrounds or a lupus, inflammatory bowel disease, multiple sclerosis, our innate immune system is active.

And we know that increased inflammation in the brain is linked to much higher rates of anxiety and depression. High rates of headache and migraine. Yes.

There's so much in common across all of these systemic autoimmune diseases, you know, which is why I'm so glad you're a part of this summit. Doctor water that we have.

When I last looked, it was about 15 million people with systemic autoimmune disease.

Delayed diagnosis and long-term risks

And majority of those are women. Is that the correct number? 15 Lowballing it, I've seen numbers across the board. That's probably a nice, good middle range where we're not over and not under reporting.

Yeah. And I also see that this is coming younger and younger, for us. So, I'm good. I'm getting invited to talk a little bit about the systemic autoimmune diseases that are affecting our children.

So interesting. You know, again, going back to what we're taught. But then the reality, what we're taught to think about was showgrounds is someone who is maybe having just gone through that, that perimenopausal transition and they're being diagnosed maybe in their 50s or 60s.

That's kind of the stereotypical patient we are taught to think about. But really showgrounds and increasingly many of these different immune conditions can occur in childhood.

I have a number of folks that I have, that I've encountered talk to, including some colleagues that have been diagnosed, and even before puberty. And so it can occur across the lifespan.

Making a little note about the gender dynamics with showgrounds, we estimate about 90% of folks with showgrounds are women. But it also can affect men.

And it may be also, you know, something that again, as we're taught, this is a female disease. The gentleman showing up may not be recognized because again, our lenses are shaded by some of that is preconceived notions.

Or you know, what we learned for an exam question. The I think one of the other aspects to my my personal journey that this kind of fits into, and my mom is one of six kids and they're about ten grandkids.

And my generation now, mom's generation has the usual and usual things we think about in American society type two diabetes, hypertension, a little bit of anxiety, depression, you know, high blood pressure, those sorts of things.

Cholesterol issues in my generation, half of us have an autoimmune diagnosis. And even in my own family, we don't have any family history of food allergy.

My middle, who is now seven within two weeks of my sugars diagnosis, had an anaphylactic reaction to eggs. It's interesting to see how these kind of term misbehaving immune systems autoimmunity, allergy increase cancer rates.

All of them are on the rise and all of them coincide with this rapid shift in how we live our day to day lives. The things were exposed to. We call that whole, that whole the exposome, all of the things that were exposed to the air we breathe, the food we eat them, microplastics, the lotions and potions, all the stuff.

It all has downstream effects. You know, one of the things that families in our clinical trials, in my clinical practice tell me that they struggle with this.

You know, I realize I need to make these changes for how I'm eating and living, but it feels wrong to make my kids eat this way and miss out on, you know, the foods and treats and lifestyle that their peers are having.

Yeah. What what are you how do you have that conversation with your family and with your patients? Yeah. So I think how we've decided to handle it in our house is that we can control, in large part, what we bring into the house, and that accounts for 80, 80 to 90% of what the kids are exposed to, right?

Kind of their breakfast. They tend to not like the school lunch. So we will pack lunches and dinners.

Autoimmune disease, heart risk, and womenu2019s symptoms

And so then when there are, you know, the occasional treats at softball practice or, you know, birthday parties, then frankly, I don't stress too much because they're learning those lessons at home.

You know, they're getting a variety, whether they like it or not. All of of different fruits and veggies and fiber and proteins. And, you know, I also and very much grew up in a I'm a product of kind of the the diet culture of the now is an early 2000s.

And so I also am very thoughtful about wanting them to not have a strained relationship with, you know, good

foods, bad foods too. So that's that's kind of the the middle ground.

I've, I've tried to take also just work in progress. Yeah. You know, big, big food spends billions of dollars trying to make our children addicted to, their sugar, ultra processed foods.

And so we talk about that, and we talk about the super power of, vegetables. I have a little grandson now. So we talk about the super power of sauerkraut.

The actually like sauerkraut. And, one of my patients had this really brilliant observation that, you know, as children get into adolescence, that you go to the restaurants, they want to order food that really is that good for them.

And so my patient said, so we we developed a new plan that whenever our children when to order food that did meet the family approval for being healthy, the child had to pay for it.

At the time that it was ordered with their own money. And so they quickly decided, and that's what gives a child autonomy. They can spend their own money on stuff that's not good for them.

And the adolescent said, you know what? I want to know? How will I waste your money? I'll just. I'll eat the stuff that celery says. It's good for me, but I think it's important that we recognize that lessons do need that autonomy.

But the family doesn't have to subsidize bad decisions. So I thought that was a really I like the way resilient, brilliant move. Yeah. You know, my, my oldest is just ten, and so we're just starting to kind of explore, you know, and she's learning to exert, her autonomy in various ways.

And she definitely prefers the carrot. And so I like, and to bring that to the discussion table to the discussion, let me know how it looks, because we have to empower our children, because to get all these messages from a very young age, from big food to eat, these foods that are really terrible for their health.

So we have to continually tell them about the foods that are good for the health and why, and point out that these companies are trying to profit at the expense of their health.

So, yeah, and the interesting studies that that will tell us, if we explain to our very young children that these foods are superfoods, they are magical, that they do these great things to make our brains work better, to make our muscles stronger.

They'll believe us. Now we talk all the time about feeding our tummy about this hour. Tell me about those need need fuel. And that's what we're that we need to at least have a couple bites of, you know, whatever veggies are on the menu.

Even if we don't like them that much, we still need to have a little bit of a taste because that also is helping them and their palates expand.

Children, family habits, and food choices

We know that it can take, gosh, 20 plus exposures to different tastes to really develop a liking of different, especially fruits and veggies, fruits and vegetables. We also have liver.

We have liver once a week at our house. And, you know, it will be working on exposing my grandson to that because I want him to learn that liver can be, really quite a delicious food.

But it's a process to bring your children along. Another tool that, was introduced was in middle school, so it's had my kids helping to make make meals.

My favorite things to do in middle school, we had our kiddos have to make a meal with adult help. And then in high school, they had to select a recipe.

I'd have to prove it best to make sure it was. It would be good. And then I could be their sous chef. They really love bossing me around, so help them with their meal plan.

Having your kids learn how to cook, shop, meal plan. Really vital skill. Yeah, I'm very fortunate that they have had fun doing that. You know, one of the first things I remember, my oldest was three and a half or four around the time of my diagnosis, and we I had my husband build one of the little stands so that she could she could get up and stand at the counter to be at counter height with me.

And I remember her mashing avocado with a fork, and that was kind of one of her first forays into helping contribute to dinner was helping make guacamole for, for fajita night.

That is such an important thing for our children's one. I think they all need to have chores. It's good for them. And helping them learn how to cook can have fun.

Cooking helps, be excited about the foods that we're eating and teaching them to value and enjoy. Yeah, one of my big aspirations as we come into this spring and summer, we moved, about a year and a half ago.

And so, I think on on the docket this year is, is getting a garden planted because that's been at our prior house, we had a garden space and getting them out in the dirt, exposing them to, dirt is very helpful from an immune system standpoint, but also contributing to, helping with tours and again, seeing where their food comes from.

And there is nothing more fun than watching them eat the pods, you know, right off the vine. Wonderful. Well, as we begin to wrap this up, what is the key message you want people to remember about show gardens?

I think one how it is not rare, it is just rarely thought of, rarely diagnosed and really, advocating for yourself. I think knowing the data is very helpful, especially that 30 to 40% of folks will have normal bloodwork.

You now have some, and then the names and the, the language to be able to share that with your care team, and continue to learn and advocate, because having having a name, for what you're living and what your lived experiences really does have immense impact in your ongoing health and care.

You know, there's just one more concept I want my listeners to be aware of.

Key takeaways and resources

If you have one autoimmune diagnosis, you're more likely to get another autoimmune diagnosis and then a third and a fourth, particularly if you are doing the functional medicine lifestyle medicine approaches to managing your autoimmune disease.

So for the most listeners, do you think I have a muscle? Don't have to worry about this. Unfortunately you do. Yeah. Yeah. The the zebras like to travel in herds.

Yeah. So how do people learn more about you, Doctor Wada? And, can you tell us about your website and what you've got? Coming up? Yeah. Thank you so much.

So, over at Doctor Cara Whatcom, you'll be able to find a great resource which is, show run starter kit. It's all of the tools and resources I've collated over the years that I would have loved to have when I was first diagnosed, or even exploring that diagnosis as a possibility.

And I also, hosted a virtual showgrounds summit, very similar to how this works, where it's free to attend lots of great speakers and information, really empowering folks to one know about new treatments that are on the way, but also empowering them to be able to use their habits for healing.

Okay, thank you so much. This has been really wonderful. Thank you so much, Doctor Wahls.