Understanding Sjögren's: What I've Learned Along the Way

Shilpa Venkatachalam (00:02:25:10 - 00:03:21:11)
Welcome to The Sjö, pronounced “show,” and I have to draw everyone's attention to this very cool title. This is a podcast on Sjögren’s and so we're calling it The Sjö. Driest pun ever possibly in the podcast world. This is a new podcast series from the Global Healthy Living Foundation, created for anyone living with, caring for, or trying to understand Sjögren’s disease. Whether you're newly diagnosed, still searching for answers, or supporting someone who is, this series is here to help you feel less alone and more informed every step of the way. My name is Shilpa Venkatachalam, and I am GHLF’s Chief Patient Centered Research and Ethical Oversight Officer and Principal Investigator of our PatientSpot Research Registry, and I will be your host for this series.

Shilpa Venkatachalam (00:03:21:12 - 00:04:20:12)
In this first episode, “Understanding Sjögren’s: What I've Learned Along the Way,” we're starting with the question so many patients ask first: what's happening to me? We’ll walk through what Sjögren’s is and just as importantly, what it isn't, along with why diagnosis so often takes longer than it should. We'll also cover the science clinicians look for, the lab work and testing involved, and the symptoms that go far beyond the dry eyes and dry mouth that most people associate with this disease. Finally, we'll also talk about why there's real reason for optimism right now, from growing awareness among doctors to emerging treatments and a rapidly growing patient community. So we hope by the end of this episode, you'll walk away with a clearer picture of what's going on in your body and the sense that you are not navigating this alone.

Shilpa Venkatachalam (00:04:20:14 - 00:05:19:00)
Today's first guest is Dr. Priya Reddy, a rheumatologist in private practice in Tampa Bay, Florida. With over two decades of experience, Dr. Reddy specializes in caring for patients with complex rheumatological conditions including rheumatoid arthritis, psoriatic arthritis, lupus, and Sjögren’s disease. She's also passionate about the role lifestyle plays in managing chronic illness, focusing on nutrition, sleep, movement, and stress management alongside traditional treatments, all very important dimensions of the disease management process for patients. Beyond her clinical work, Dr. Reddy is Immediate Past President of the Florida Society of Rheumatology, Secretary Treasurer of the Association of Women in Rheumatology, or AWIR, and a faculty member helping trained the next generation of physicians. We're delighted to have her with us. Welcome to you, Dr. Priya Reddy.

Dr. Priya Reddy (00:05:19:02 - 00:05:21:05)
Thank you.

Shilpa Venkatachalam (00:05:21:07 - 00:07:02:14)
Our next guest is Melissa Taylor, known to her community as Autoimmune Auntie, an actress, content creator, and Sjögren’s patient based in North Carolina. Melissa started experiencing symptoms at just 20 years old. But it took four long years of being told it was just anxiety, which we'll talk about more, before she finally received her Sjögren’s diagnosis. That journey came with its own kind of isolation, not just physical, but emotional as well, as she found herself

confronting fears about her health that many people around her couldn't relate to. Today, Melissa uses humor and honesty to make content about life with chronic illness, and she's become a powerful voice for something many patients feel but rarely hear said aloud: that invisible symptoms don't mean an invisible illness. As she puts it, just because it's less obvious from the outside doesn't mean it isn't severe. Very warm welcome to you, Melissa.

Melissa Taylor (00:07:02:16 - 00:07:04:04)
Thank you so much.

Shilpa Venkatachalam (00:07:04:06 - 00:07:41:10)
So once again, thank you both for being here today. And we're going to have a conversation here about Sjögren's, understanding Sjögren's, pathway to diagnosis. And I want to start with you, Dr. Reddy. So for someone who is hearing about Sjögren's for the first time in our audience, how would you explain what Sjögren's is, what it isn't, and now you know, given that, and now, because it's been called a disease and not a syndrome, how can we talk about it in a way that's different to how it's been spoken to, spoken about in the years previous?

Dr. Priya Reddy (00:07:41:12 - 00:08:38:23)
The first thing is Sjögren's disease, the name has changed. Like you talked about it, it used to be called Sjögren's syndrome or sicca syndrome. Sicca is the word for dryness. And just for those who want to be cleared, clear on the pronunciation, it's Sjögren's, it's pronounced Sjogren's, and it's got an S J with a O that has two dots over it. And that's very complicated and I see that first of all is like the first point, stopping point for a lot of people, that, "What? How do you spell that? You know, what? How do you actually say that?" So I want to clarify that it's pronounced Sjögren's. And it used to be called these other names, Sjögren's syndrome, sicca syndrome for the dryness component of it, and is now called Sjögren's disease.

Dr. Priya Reddy (00:08:39:01 - 00:09:51:11)
I think that change is really important to focus on in the way that we refer to Sjögren's as a disease. Because when we refer to something as a syndrome, even within the medical community, and oftentimes as patients kind of look it up, it sounds for a lack of a better way of saying it, you know, less important than it actually is when you just call something a syndrome. And syndrome, as doctors have learned in medical school, is actually a constellation of signs and symptoms. Whereas this is a complex chronic autoimmune disease that has a pathology in the body that actually characterizes it as a disease that is actually now not just sicca, or dryness, which is the, you know, predominant presentation for most patients, the dryness of the eyes and dryness of the mouth, and really dryness that is in other areas as well, but it constitutes other symptoms that go beyond just the dryness.

Dr. Priya Reddy (00:09:51:12 - 00:11:12:12)
But understanding that it is a complex disease with a pathology that is still the understanding of it is still evolving. And I think that's really important for patients to understand that it is one of our autoimmune rheumatology conditions. And I make a point of saying those words very specifically for rheumatologists. We treat autoimmune rheumatologic conditions, autoimmune meaning where the immune system, for whatever reason, decides to attack the body's, you know, organ systems. I say that the immune system has to do one thing really well before anything else,

and it should know what belongs in the body and what doesn't belong in the body. And in patients who have auto immune conditions, we don't know why they have these conditions, why one twin has an autoimmune disease and the other one does not. But it involves an attack of the body. And rheumatologists don't treat all autoimmune conditions. We have our own specific set of conditions that we treat. And Sjögren's is one of those conditions.

Shilpa Venkatachalam (00:11:12:14 - 00:11:54:22)
Wow, thank you. You broke that down really well for us. And I want to come back to a few things that you touched upon. You know, this perception that it's only about dryness is a big one across communities. And we'll come back to that. But before I come back to that, Melissa, can you talk to us a little bit about, you know, when you think back to the time before you were diagnosed, what were some of the symptoms or challenges that you were living with, and when did you realize or start to realize, "Wait a minute, this might be part of something bigger. You know, there might be something else that's going on." Can you talk a little bit about that, please?

Melissa Taylor (00:11:55:00 - 00:12:45:15)
Yeah. So, it was a really strange time in life. I was pretty young when my symptoms started to be impossible to ignore. Some of my first symptoms were actually vertigo and dizziness. So I remember I had this two-week period where I was so incredibly dizzy that the room would actually spin, and so it made it really hard for me to make it to classes. And there was about two weeks in there where I was pretty much bedridden. Just so dizzy and I didn't know what was happening. So, of course, I went to the doctor and they said, "Well, that's vertigo. And it's usually a symptom of some kind of underlying condition, but we don't know what underlying condition that might be."

Melissa Taylor (00:12:45:17 - 00:13:33:18)
So I remember at the time, they gave me something, and I don't remember what it was called, just to control the dizziness. And luckily, I have episodes of vertigo every now and then, but I don't have it all of the time. So it was very confusing. It had nothing to do with dryness at that point whatsoever. I was just very dizzy. And then the next kind of red flag, sign, I would say, was I started to have this really severe fatigue to the point where I could not hold a conversation with someone. Like if the conversation was very animated and required a lot of thinking things through, I was too tired to actually do that. So that was another big red flag for me.

Shilpa Venkatachalam (00:13:33:20 - 00:14:10:05)
Thanks, Melissa. You know, there are a few important things that you touched upon, and I want to come back to you, Dr. Reddy. Like Melissa, people who are listening in here are people who might not have a diagnosis as well. What should they know about how this disease presents itself? Because, as Melissa said, she did not experience the typical dry mouth, dry eyes sort of symptoms. She had the vertigo and the dizziness, the fatigue. So what should people keep an eye out for in terms of what it might present as?

Dr. Priya Reddy (00:14:10:07 - 00:15:15:03)
Yeah. So I think that this is a really sort of nice example of how patients eventually come to see a rheumatologist. And when we interrogate the sort of full spectrum of symptoms, we're able to kind of pull at different things that may have been significant in the past, and they may be related

to what's going on right now. So first thing that I would say is Sjögren's would not be the first disease that somebody thinks of when a patient presents with vertigo. So it is not the common presentation. There are, you know, the majority of patients, the 80% or more patients have the dry eyes, dry mouth. Fatigue is one of the big, you know, falls into that 80%, along with arthralgia, which is joint pain or diffuse sort of pain.

Dr. Priya Reddy (00:15:15:07 - 00:16:26:14)
So the first thing that I could say is that it is very, very typical, your experience, Melissa, is very typical of having symptoms and going down a particular path of working up those symptoms. And then eventually you get hit with this fatigue. And I want to speak to that for just a minute, because the kind of fatigue that is experienced by patients who have Sjögren's and is really the sort of overwhelming fatigue that you are describing. I always tell patients, you know, fatigue is the box that every single person in my office who walks through that door is going to check. I mean, everyone, and me on most days as well included, we'll check that box for fatigue. But it's different when someone has a level or severity of fatigue that does not really fit with, you know, "I didn't sleep well for three days. I'm tired," or "I'm a chronic sort of go, go, go person all the time. And finally it's hit me and I'm tired." That extent of fatigue and paying attention to that, I think is really important.

Dr. Priya Reddy (00:16:26:18 - 00:17:42:19)
Having said that, the other kinds of things that as a rheumatologist, I sort of ask patients about is, of course, the dryness. So when we're talking about those sicca symptoms, you know, are you having a burning sensation? Do your eyes feel gritty or sandy? Is there ever redness or a change of vision because of how dry they feel? Do contact lenses, you know, come out by the end of the day? And are you having a lot of trouble when you're getting them off? It feels very, sort of dry. The oral dryness can be so severe, the patients can't swallow food unless there is liquid. It could be that extent of dryness at night, needing to drink water. And other things when I look for the extremes of those presentations would be: have you ever had a corneal ulcer in your eye or had a diagnosis of keratitis? And oral, I ask for: have you noticed that you have suddenly a lot of cavities? You know, you were fine for a long time and then suddenly it's cavities. You're seeing the dentist and they're telling you. "Wow, you're really dry and you've got suddenly cavities" and you've been fine all along.

Dr. Priya Reddy (00:17:42:21 - 00:18:59:18)
But other things that are important to think about are salivary gland swelling. So it's parotid gland enlargement. So sometimes patients will say, "Yeah, someone thought that I had the mumps or something, you know?" And I'm like, "Oh, how many times did they think you have the mumps?" That could be a clue. And then other areas of dryness as well, like cough, hoarseness, vaginal dryness. This is still kind of going along that dryness, fatigue syndrome with the salivary enlargement. But what's important is that there are, like we were talking about Melissa's presentation, what we call systemic or extraglandular involvement, which we could see in about 50 to 60% of patients. And it can be severe in about 20% or so. And some of those manifestations, one is the fatigue, but it can affect other organ systems as well. There can be the arthritis, there could be skin involvement, nerve involvement, lung or even kidney involvement. So this is a, like I said, it's a primary dysfunction, dysregulation of the immune system and its impact can be involving other organ systems.

Shilpa Venkatachalam (00:18:59:20 - 00:19:57:06)
Great. Thank you for breaking that down. So it sounds like there's a constellation of symptoms attached to various different organs, which is why this is not just about dryness. This is kind of a systemic disease. And I want to come back to you because you talked about fatigue. Melissa, you talked about fatigue as well. You know, some of these symptoms, I live with RA, for example, and I experience a lot of fatigue. So I do want to come back to you and talk about diagnostic, you know, sort of biomarkers and how this disease is diagnosed. But before that, Melissa, you had said in a, you know, you had told us that it took four years for you to get a diagnosis. Did getting a name to what you were experiencing change anything for you, how you related to, you know, the symptoms, the disease, your own body? I'm sure there was, you know, conflicting emotions. Can you talk a little bit about what that process felt like?

Melissa Taylor (00:19:57:08 - 00:20:48:21)
Oh my God, yes. There were so many feelings. The first feeling I felt was relief. Like, thank God somebody finally put a name to all of this crazy stuff that's been going on in my body I didn't have a name, I didn't have language for. So during that four-year period, it's like, it is hard to carry on with a normal life, especially if you are, I mean, just any point in life really, but I was in my early 20s. So I couldn't even, I don't know. Yeah. It's interesting to look back. But first relief and then there was anger because I had been going to the doctors during that entire period of time and getting just all of these random diagnoses, of course, anxiety being one. And that became the focus.

Melissa Taylor (00:20:48:23 - 00:21:35:07)
And so I had this anger for those years that I felt that I lost. And then that anger just propelled me to sort of use my experience to try and get the word out that Sjögren's can look different than people expect it to. And that's what happened for me. And I did eventually develop the dryness to the point where I noticed I had it. And I probably had it all along, but it was so gradual and so slow over time that I didn't even realize that I was dry. The doctor had to tell me I was dry. They had to do the dry eyes, the Schirmer test on me. And it came back, not impressive. And so then they told me that I did in fact have dryness.

Shilpa Venkatachalam (00:21:35:09 - 00:22:35:18)
So, you know, Melissa, you touched upon something that we hear a lot from the patient community. This, you know, this input when you first start experiencing the symptoms, it might be all in your head. It might be depression. It might be, you know, you might, nothing's wrong with you. Come back after a few months or what have you. Dr. Reddy, for people listening out there, how does the diagnosis actually happen? Are there specific biomarkers, blood tests? Are there certain things you're looking for? Because a lot of us with rheumatological conditions face years of delay before we get a diagnosis. And there's also often an overlap. What we hear from the patient community is someone gets diagnosed with RA, then they're told it might be PsA, then they're told it might be Sjögren's. So can you help us navigate that a little bit and understand from the clinician perspective what some of the challenges might be?

Dr. Priya Reddy (00:22:35:20 - 00:24:03:17)

Absolutely. I think there's a lot of challenges in making a rheumatology diagnosis. Shilpa, as you absolutely pointed out, this is not unique to Sjögren's disease. This, really this delay in diagnosis is a symptom, for lack of a better word, so I'm making puns today as well, is a symptom of having a chronic rheumatologic condition. I'm going to try, as best I can, to interject a little bit of history into rheumatology. If you look historically at the evolution of rheumatology, it really... Rheumatologic diagnoses were really only constellation of signs and symptoms. So patients were given a label of having rheumatoid arthritis, for example, if they fit a constellation of signs and symptoms or they had that phenotype, you know, it was a phenotypic diagnosis. And what that means is patients would have, you know, morning stiffness, bilaterals, small joints. There's a way that we would describe and there was criteria that were clinical criteria for a diagnosis.

Dr. Priya Reddy (00:24:03:20 - 00:25:18:13)
As we started to evolve the field and look more closely at patients and develop technology, and, you know, it starts with lab medicine and, you know, evolving imaging studies, and then understanding the immune system better, we're able to better understand what causes some of these symptoms.

Dr. Priya Reddy (00:25:18:15 - 00:26:35:05)
So I think it's challenging for patients also, because rheumatologists are highly specialized. There's not a lot of us out there in the community. It's very difficult to get an appointment with a rheumatologist. And because our diseases are so complex, generally physicians don't know enough to even know that maybe we need to send this to a rheumatologist. So there's, you know- and imagine that our conditions can involve the eyes, can involve the heart, the lungs, the joints. So you're talking about a lot of different specialists who are then required to know some rheumatology and know when to refer. So it is very, very common and very easy for patients to get sort of lost in that maze of specialists until they even see a rheumatologist. And then when you see a rheumatologist, you're talking about these complex conditions where we are really kind of wearing our detective hat and seeing what fits into this particular disease and what doesn't.

Dr. Priya Reddy (00:26:35:07 - 00:27:29:06)
And like I said, you know, I've got certain clues and cues that I'm listening to that's going to increase my suspicion for a certain diagnosis. And then, of course, there's all of these different things that we do to test patients to determine whether they have it. And so there's, you know, the objective sort of test that we do for dryness. Sometimes it's not just the Schirmers, but I have to have them go back to ophthalmology for, you know, testing to look for ocular staining. Sometimes a biopsy is necessary if there isn't obvious kind of symptoms. And, you know, the blood markers, we look for SSA antibodies, SSB antibodies after we've tested for an antinuclear antibody. If that's not classically there, we may need that biopsy to assess.

Dr. Priya Reddy (00:27:29:12 - 00:28:09:19)
We've got to make a case for the disease. Because, remember, once we diagnose our patients with our disease, it's forever. It's a forever diagnosis. This is not going anywhere. And the treatments that we're going to start recommending are immunomodulatory. There's risks involved with those treatments as well. So we want to be very careful about making the diagnosis as well. to make a case for the disease. Because, remember, once we diagnose our patients with our disease, it's forever. It's a forever diagnosis. This is not going anywhere. And the treatments that

we're going to start recommending are immunomodulatory. There's risks involved with those treatments as well. So we want to be very careful about making the diagnosis as well.

Shilpa Venkatachalam (00:28:09:21 - 00:29:00:09)
Sure. And I mean, it sounds, I know you use the analogy of lawyer. For me, it sounds more like detective work in all these different pieces together. So you're all detectives, multi-specialty detectives, you know. And we'll talk in subsequent episodes also about the role of communication with your clinician. We have at Global Healthy Living Foundation an app and a platform called PatientSpot. And we always encourage the community, myself included, I use it regularly well, to keep track of what happens in between your appointments. But also maybe, you know, when you start experiencing symptoms, to sort of record those symptoms so it's easier to communicate them to your doctor at your appointment.

Shilpa Venkatachalam (00:29:00:11 - 00:29:29:11)
Melissa, I want to come back to you. You know, you said you talked about, how it took, to Dr. Reddy's point, how it took a while for you to get this diagnosis, right? And it caused anxiety, etc. What do you wish someone had told you when you were first diagnosed that would have made those earlier days a little bit easier if you think back? I know it's a bit of a tough question, but just looking back.

Melissa Taylor (00:29:29:13 - 00:29:56:11)
Looking back, what do I wish someone had told me? I think at the time I really needed to just hear, “This isn't in your mind. There is something happening. We may not know what that is, but we're going to figure it out.” I think I really could have used those things. “We believe you. There is something happening here. We just don't know what yet.”

Shilpa Venkatachalam (00:29:56:13 - 00:30:47:09)
Yeah. And again, Dr. Reddy, to Melissa's point, this is something that we consistently hear from the patient community is people, and obviously from your explanation it's not intentional, these diagnosis and the process to diagnose these conditions sounds very complicated, but patients often feel dismissed is the resounding kind of message that we hear over and over again. Symptoms are all in your head. Especially when it comes to pain. You know, we want to talk about what would your advice be? How can patients communicate what they're experiencing to their healthcare team better? And what would you say, you know, when someone is diagnosed with this disease, what should they expect? What does managing this disease look like?

Dr. Priya Reddy (00:30:47:11 - 00:32:08:12)
Yeah. So I think that's a really... I love the honesty of your answer, Melissa. I think that a lot of patients do not feel seen or heard when, you know, it's dismissed or you're going to several providers without an answer. And this is common for I think patients in general. And one of the things that I have to remind myself too, because as a doctor, like, I want to be able to help my patients, and I also want to be able to make a diagnosis. I mean, every physician wants a clear diagnosis, okay? Rheumatology lives in the zip code of ambiguity. I mean, we are taught in medical school that patients don't read the books. And I love that that term, because the point is that your patient is not going to follow a textbook pattern of disease. And you should always

remember that. And I like to keep things open-ended and always sort of an open mind when patients come in with different symptoms.

Dr. Priya Reddy (00:32:08:18 - 00:33:22:06)
But I think that one of the things that is a difficult thing to kind of communicate or articulate is just because there isn't a diagnosis doesn't mean it's not happening. You know? And that's something that I'm very, very explicit about telling patients. You know, I told you about the history of our rheumatologic diseases. All those patients had disease. We just didn't know what to call it yet. You know what I mean? So it is important for patients to just, I think be very honest, open. I always encourage patients to kind of journal their symptoms. In fact, I try to tell them, you know, just kind of keep track of, you know, one day it was worse. You know, just kind of the scale of your pain, the scale of the fatigue. Were there other things that kind of, were around those days that where you can see patterns? You know, I love that sort of journaling. You know your body better than anyone else. And so journaling that becomes, you know, really sort of important.

Shilpa Venkatachalam (00:34:19:13 - 00:34:24:23)
What can patients expect in terms of how this disease is managed clinically?

Dr. Priya Reddy (00:34:25:01 - 00:35:29:14)
Yes. Yeah. So, the management first really begins on the specific, areas of involvement. So since our conditions involve different areas, we kind of start with if there is dryness of the eye, for example, topical regional things that will improve that dryness to prevent keratitis and corneal ulceration and follow up with ophthalmology because they are going to be much better. And they have the tools in their doctor's bag to actually track those different symptoms better than a rheumatologist would. You know, different things for, you know, lozenges are better, actually, than a lot of water, you know, for mouth dryness and treating that with treatments like anticholinergics, for example, to kind of increase the secretion and preventative care in terms of avoiding carries and cavities of the teeth.

Dr. Priya Reddy (00:35:29:14 - 00:36:53:06)
But other things like if a patient has joint pain, there may be a role for simple Tylenol or, you know, acetaminophen or NSAIDs. Treating neuropathic pain with neuropathic medications. NSAIDS, if there's a lot of inflammatory sort of joint pain. There may be a role for what we call conventional synthetic DMARDS. These are your methotrexate, azathioprine for steroid-sparing. If patients are so severe that they're getting steroids, which I will tell you right now, steroids are sort of a blessing and a curse. They make patients feel really good. But long-term, the side effects of steroids are terrible. So we may opt for, you know, these DMARDS that are conventional synthetic as steroid-sparing agents. And then, of course, you know, there's the big heavy hitters for more systemic involvement. So it really, what the rheumatologist is going to do is determine the severity, the areas that are involved, and tailor to more regional therapies if there's like, if there's a containment in just certain areas. And then look more like, “Okay, let's look at immunosuppression or immunomodulation overall because this patient has a big load of systemic disease in addition to regional or just systemic, primarily.”

Shilpa Venkatachalam (00:36:53:08 - 00:38:01:06)
Lovely. And, you know, you said a few really important things that I want to reiterate for the audience. One is, you know, rheumatologists live in a zip code of ambiguity. So it takes a lot of different pieces to understand what the diagnosis might be. You know, just because it does not have a name doesn't mean it's not real. I think this is something that's going to resonate very strongly with the patient community. And, you know, that kind of message is what I think patients want to hear about. And then, of course, you know, all these different ways of managing the disease that becomes really important. As we're approaching sort of the, you know, the end of this podcast, few more questions here. Melissa, can you talk a little bit about when you talk to your healthcare team about your symptoms, do you feel well understood? Are you able to communicate your symptoms now that you've been living with this disease for a while better, or do you still have challenges communicating, you know, the symptoms that are burdensome or or not being taken care of?

Melissa Taylor (00:38:01:08 - 00:39:36:02)
Yeah. So, I thought that getting a diagnosis and having a label on it would help more in caring for the disease. Because I thought, "Oh, good, they know what this is. That means that A plus B equals C. That means there's a solution, right? Like I'm going to feel better." And my journey has been way more, less clean than that. So now I have a phenomenal PCP. I trust her literally with my life. She's amazing, and I tell her all of my symptoms. And I just appreciate her so much because I know she will take them seriously. And I think at first I was really running into what I like to call the "branding issue" with Sjögren's because it was at the time a syndrome. And I did have some encounters with doctors who truly believed in their hearts, their heart of heart that that was it. Like it starts and stops with dryness. And if I brought any other symptoms into the picture, it was just sort of like, "Well, that's not related to Sjögren's," sort of end of conversation. I am finding that less now. And, you know, I'm better about picking out the questions I want to ask my team to see how much do you know about Sjögren's? Because I know that there is still evidence emerging. And I have not had that issue as of late.

Shilpa Venkatachalam (00:39:36:04 - 00:40:41:21)
Thank you. Yes, I think that was a really powerful way to say it is A plus B equals C. It's never that straightforward with any of these rheumatology conditions, I suppose. You know, and this is why we also repeatedly encourage and advocate for direct-from-patient data, the lived experience. How do we communicate the lived experience and set goals that are important to us as patients? And so the importance of tracking your symptoms, whether it's through PatientSpot or through any other app. I think we've come back full circle here when Melissa talked about this optimism around the change in nomenclature, right? Now it's a disease. It's been designated a disease. Dr. Reddy, there seems to be now a growing sort of, there's a momentum building now. There's growing awareness and research around Sjögren's as a disease. What are you most optimistic about in the future for people living with this disease?

Dr. Priya Reddy (00:40:41:23 - 00:42:00:11)
So I'm certainly optimistic about it. And I mean, I think just the fact that we are having a podcast on Sjögren's, and it's got this cool name, Sjö, you guys have the S J O on there, Sjö, you know, reiterating how it's pronounced. And we're creating awareness, in other words. I think that's really the first step is patient awareness, the medical community awareness. And I think

spreading the word that this is a condition that we are now developing treatments for, and the paradigm is shifting and our understanding of it. And so the shift will also be in the way that we approach and treat this, I think is what gives me the most optimism. I think that it's very exciting to be a rheumatologist, because there are so many innovative treatments that are on the horizon and that are, you know, right around the corner as well for a lot of the conditions that for, you know, decades, we did not have a lot of movement on in terms of treatment.

Dr. Priya Reddy (00:42:00:11 - 00:42:51:19)
But what is very exciting for me is that as we have newer treatments, that target, you know, certain pathways of the immune system, our understanding of the disease itself starts to grow and change. And I think that's really where the key is, where we move from this sort of "this is the syndrome and that clinical presentation of the patient" to "this is the scientific explanation, you know, for these symptoms." And as we get closer and closer to that, I think we can serve our patients better. And that's very exciting for me as a clinician and a, you know, person who deploys science every day with patients.

Shilpa Venkatachalam (00:42:51:21 - 00:43:29:03)
Love that, a person who deploys science. Yeah. I mean, such, such an optimistic note. And I want to actually, as we wrap up this episode, bring you both to one question, kind of looking ahead, but also looking back. If you could go back to the beginning of your journey, Dr. Reddy, for you as a clinician, Melissa, for you as someone who lives with the disease, what is one thing you wish you had known then that you know now? Melissa, let's start with you.

Melissa Taylor (00:43:29:05 - 00:44:23:07)
Oh gosh, I feel I've learned so much. I, you know, the point that I was at in my life, I did not fully have the confidence and the knowledge of my disease to say, "I'm going to go seek another opinion." And I wish that I had. I guess that that's what I had in the very beginning, because I think it could have saved me some time. Because somebody was going to get it. And I got very lucky and it was actually a nurse practitioner who caught it because she herself has lupus. And when I came into her office with all of these weird, seemingly unrelated symptoms, she caught it right off the bat. So I think that I wish that I had had sort of the confidence to know when something is working well for me and when it's not.

Shilpa Venkatachalam (00:44:23:09 - 00:44:44:21)
Wonderful. And Dr. Reddy, you alluded to this, is that patients know their bodies best. So, you know, if you feel like something is wrong, pursue, pursue until you get an answer. But I want to bring the same question to you, Dr. Reddy. From your clinical expertise what is it that you would like people to know?

Dr. Priya Reddy (00:44:44:23 - 00:46:29:14)
I mean, I think that I want people to know that rheumatologists, we really want to be able to diagnose and treat. And that we are working really, really hard to understand these diseases better so that we can better serve our patients. But we have still a little bit of a ways to go. The immune system is complex. It is not isolated to one specific area of the body, and it can have effects, you know, from head to toe potentially. And we don't know fully why certain conditions are predisposed to certain organ systems versus others. And we're still understanding that. I want

patients to really, you know, continue to advocate for themselves, for their family members. When things don't seem right, you know, let your physicians know. You know, if I see a patient for the first time and I feel like, “Okay, I'm not getting a feeling that this is Sjögren’s disease,” for example, I will still defer to the doctor who's referring that patient to me because I say, “They know you better than I do. They've seen you even once or twice more than I have,” you know?

Dr. Priya Reddy (00:46:29:15 - 00:47:28:11)
So I think that we are still continuing to further the field and trying to understand this complex disease better. And, you know, if I had, you know, the question of what is one thing I wish I knew? I wish I knew that we would have all these exciting treatments, you know, for Sjögren’s. And it would have at least made me feel more hopeful. Because it is very frustrating, even for a rheumatologist, to have a patient who has, you know, extraglandular involvement, systemic involvement and seeing that we're not getting the response that we want on the treatment. So, you know, there are some patients who I wish we had those treatments then that we have now for when I reflect on my kind of experience with Sjögren’s disease.

Shilpa Venkatachalam (00:47:28:13 - 00:48:27:11)
Yeah, thank you. And I think for the, you know, for the patient community, it's also important for us to understand and I, you know, I'm speaking of myself here as someone who lives with an autoimmune condition myself, to understand from the clinical perspective that these diseases are not straightforward and easy to diagnose. So thank you for the continued research and the clinical work that you all do each day, every day to help make our lives better. And, Melissa, thank you so much. I, you know, I want to wrap this up by saying thank you to both of you for joining us today and for sharing your expertise, Dr. Reddy, on Sjögren’s. Melissa, the generosity and the honesty with which you have shared about your own journey and your disease is really very, very touching. It really moved me. So thank you for being so honest in your communication and sharing that so generously with us today.

Shilpa Venkatachalam (00:48:27:13 - 00:49:32:19)
Conversations like this one are so important for helping our community feel seen, feel understood, and feel equipped really to advocate for themselves, something that we talked about over and over again. And we're really, truly grateful for this conversation, for your time, and your insight. And to everyone listening in, thank you for tuning in. If today's episode resonated with you, we invite you to explore more resources on Sjögren's disease and self-advocacy, and to listen to our next episode of The Sjö. Subscribe to The Sjö or visit www.creakyjoints.org for the latest information and news about living better with Sjögren's disease. This podcast was made possible with support from Novartis. If you like what you've heard, be sure to rate our podcasts, write a positive review, and spread the word by sharing it with your friends and family. It'll help more people like you find us. Thank you very much and have a good rest of your day.