Moving Forward: What Should I Do Next?

Shilpa Venkatachalam (00:00:59:04 - 00:01:35:18)
Joining us again are two voices you've already come to know. Dr. Dana Direnzo is an associate professor of clinical medicine in the Division of Rheumatology at the University of Pennsylvania, where she serves as Chief of Rheumatology at Penn Presbyterian Medical Center and as a member of the Penn Sjögren's Center. Her clinical expertise spans Sjögren's disease, rheumatoid arthritis, myositis, and scleroderma, and she brings a holistic approach to care that considers the whole patient, not just the disease. Please welcome back, Dr. Dana Direnzo.

Dr. Dana Direnzo (00:01:35:20 - 00:01:55:05)
Thank you so much for having me.

Shilpa Venkatachalam (00:01:55:07 - 00:02:20:23)
Melissa, let me come to you with the first question. So, you know, you've received your Sjögren's diagnosis, think back to that time. What would you say helped you move forward? What were some of the first things you did, you know, to get acquainted about the disease? To learn more about how to manage it, build your care team. What were some of the first things that you remember doing?

Melissa Taylor (00:02:21:01 - 00:04:04:15)
Well, the first thing that was really helpful was just that feeling of relief having a name to put on it, to understand that there was something going on in my body. That was profoundly helpful. And then from there, I had a really good nurse practitioner. She had lupus herself, so she understood sort of what I was dealing with through that lens. So that was really helpful. And then I was referred to rheumatology. I had a couple different rheumatologists because I had moved from Los Angeles, and then I was, let's see, yeah, back in Arizona after that. So I had one rheumatologist in Los Angeles. And then, when I moved back to Arizona, I got settled in with another one. And I think just having sort of back then, there weren't many options sort of for me to, to really manage the disease. So a lot of questions that I had, I ended up turning to patient communities to find sort of answers. For Sjögren's, the treatment option is basically hydroxychloroquine, which is, from my understanding, a anti-malarial drug. And so I do take that. Or there are like moisture-producing drugs you can take too. Pilocarpine is one. I have that prescribed. I do take it sometimes, but I like to try and keep the amount of medications I'm on low. That's just a personal kind of preference, but I will take them if I need them.

Shilpa Venkatachalam (00:04:04:17 - 00:04:33:16)
Very important things that you touched upon. Dr. Direnzo, you know, she talked about a nurse practitioner. She talked about the rheumatologist. In the previous episodes, we've talked about a dentist, about an eye doctor. So I want to ask you, what does a good Sjögren's care team really look like? And what role does a rheumatologist play in managing the disease if there are so many other specialties involved as well?

Dr. Dana Direnzo (00:04:33:18 - 00:05:39:12)
So a good care team should be one that works for you. And the number of people on your care team actually varies per person. So you have to understand where the patient is coming from.

Maybe even the time they have on their hand, because quickly you can accrue many people to your care team, and that adds up to a lot of appointments. So everything is going to be what is going to work and be in the best interest of the patient? I would say at a minimum, you're going to really want to have a good eye care team, ophthalmologist on your team because that's going to be important and that's going to be a physical exam niche that the rheumatologist cannot fulfill. I do not have specialties in the equipment to really do a good eye exam, to tell you and to point you in the right direction of what you need for your eye care. And then the same goes with your oral health. So we really need to lend ourselves on those two members. So I would say everyone needs to have good oral medicine and an ophthalmologist or an eye care team.

Dr. Dana Direnzo (00:05:39:16 - 00:06:37:04)
However, how Sjögren's manifest for you, the patient, is different for everyone. So some people might have a neurologist, some people might have a dermatologist, some people might have a pulmonologist. So you're going to have to really work with your rheumatologist. And especially in the beginning, so this kind of question is "What happens? I got the diagnosis." We have to understand exactly how Sjögren's is impacting you now. And that might change over time. So the size of the care team differs per patient, but I would say at a minimum everyone has to have an eye care member on their team as well as oral medicine.

Shilpa Venkatachalam (00:06:37:09 - 00:06:45:15)
Really interesting. And then sort of it builds out depending on what other symptoms you might be experiencing, what other organs might be involved.

Dr. Dana Direnzo (00:06:45:16 - 00:07:10:21)
Correct. So the rheumatologist should really be the quarterback, if you will, the organizer. So you would oftentimes, you know, float your questions and what you're, you know, trying to work on or think about what's happening in your body. Your rheumatologist should be your first point of contact for that. And then we'll get you coordinated with other specialists as need be.

Shilpa Venkatachalam (00:07:10:23 - 00:07:45:18)
Lovely. And Melissa, has that been your experience? You know, you talked about seeing different types of doctors, for lack of a better word. Is there anything that you'd like to share with the audience who's listening in, many of whom might be patients or caregivers about how you found working with your rheumatologist? How do you, for example, make sure that your concerns are heard during appointments so that they can then direct you to the right specialty care for treatment to do with your eyes or what have you?

Melissa Taylor (00:07:45:20 - 00:09:08:07)
I think that it's important to sort of ask questions. Personally, I've found that it doesn't seem that Sjögren's has a standard put in place. Because I've found different doctors will seem to understand that it's systemic and can cause other issues aside from the dryness. But there are some that have not. And so for me, it's important to sort of ask, like, have you worked with Sjögren's patients before? Sometimes the answer is no. And so for me, I'm sort of at the point in my life where I do want a doctor who has worked with Sjögren's patients and understands that it can have many manifestations. So I like to just ask questions, sort of pop in. I'm actually in between finding a new rheumatologist now. Because I definitely have, you know, a lot of other

symptoms. Like, Dr. Direnzo was talking about, all of the different doctors you see. For me, I see a GI doctor as well, because my digestive system is impacted. And I'm kind of looking for just sort of that more comprehensive care. For me, my primary care physician has really been my quarterback, and I feel lucky to have found her

Shilpa Venkatachalam (00:09:08:13 - 00:09:45:11)
Lovely. Dr. Direnzo, is that, you know, I mean, we talked about this before, where you talked about this partnership between clinicians and patients, right? Are those fair questions to ask? Because a lot of people do feel intimidated when they go in for that first appointment to ask their doctor. And you alluded to this before, is interview your doctor as well to make sure it's a good partnership. And I'll come back to preparing for appointments. But just want to ask you, as a clinician, is that a fair enough question to ask of doctors for us patients?

Dr. Dana Direnzo (00:09:45:13 - 00:10:46:01)
Of course it's a fair question. We're people too. So over time, you have to find who is going to work with you and that you feel comfortable with. I do want to also put a plug in for what Melissa said. Everyone should have a primary care doctor. That is very important. Because I actually bring this up in appointments very frequently. Not everything going on in your body is due to Sjögren's. So you don't want to lose track of your basic primary care needs. You know, like someone monitoring your cholesterol and your blood sugar and your blood pressure and all the basic primary care needs. You still should absolutely have a good primary care doctor. And yes, so we're not discounting that relationship. Because at the end of the day, your rheumatologist likely will not be also your primary care doctor. So yes, please add that to your care team and retain that as part of your care team.

Dr. Dana Direnzo (00:10:46:03 - 00:11:54:23)
So it's really difficult to have a chronic disease. And it's difficult on each part, on behalf of the patient, on behalf of the physician, to find ways to brainstorm together how to get you feeling better. So I think it is fair game to find the style you want to work with in terms of moving forward.

Shilpa Venkatachalam (00:11:55:01 - 00:12:57:10)
Absolutely. And the reason I ask that is because we've heard both anecdotally as well as through, you know, polling in the community that we've done, there is some hesitation to ask questions sometimes because of confidence or, you know, they're sometimes hesitation to seek out another opinion as well. So it's important for the patient community also to know that they are in a position to also be able to make sure who the right fit might be. So that that partnership is as strong as it really can be. So thank you for that. Melissa, you know, you talked about finding the right rheumatologist. You're in the process of having to shift and find a new rheumatologist. Once you do find the right rheumatologist, can you share a little bit about how you prepare for appointments? Is it that you go in with a list of talking points, or do you think about it before you go in? What helps you maximize those 10 to 15 minutes that you have with your rheumatologist?

Melissa Taylor (00:12:57:12 - 00:13:41:11)

I kind of think of it as like a meeting, sort of like that's how I kind of go in and I prepare. I think about like Dr. Direnzo had said, okay, what are the two things that absolutely I need to change or that I would like to have different. Because there's always something with Sjögren's. It's always doing something in my body. So I'm thinking about those things, and I just bring a couple of topics. That's mostly it. I just prepare for it like it's, you know, going to a meeting and then I like to during that, if the discussion opens up more and I see the opportunity to ask more questions, then I will.

Shilpa Venkatachalam (00:13:41:13 - 00:14:43:07)
Lovely. And you know, I want to reiterate here, both as a patient, someone who lives with a chronic condition, autoimmune condition, but someone who's been trained in research as well, the importance of tracking symptoms. Because at best, we see our rheumatologist once every three months. If our disease is doing okay, once every six months. But the period where it flares and things happen between appointments, it's really important to keep track so that we can remember to bring those points to our appointments. And so the importance of tracking your symptoms is really, really imperative. And you know, again for that we have an app called the PatientSpot app which we encourage people to use. Dr. Direnzo, from your perspective as a clinician, what are you thinking or looking for when patients come in to an appointment? What can you tell us as patients that we can do to make the most of our appointment with you?

Dr. Dana Direnzo (00:14:43:09 - 00:15:54:21)
I will give you an example of my favorite type of appointment. And then maybe that would answer this question. So at least in our clinic, but in many clinics, you'll get a question set, a questionnaire, patient-reported outcomes we call them or patient-based questions, talking about your symptoms and the impacts it’s having on your daily life. That's usually preprogramed into a lot of different appointments. And we certainly have that, for example, in our clinic. So filling them out beforehand. So I like to look at my patients beforehand and get a sense of what has been going on. Now, some of those questionnaires are based on a span of the last week or two. So you're only kind of getting current, which is fine, you know. And that's what we need to think about. Sometimes it's helpful to have a couple of them filled out, or at least journaled, the common types of interfering symptoms: pain, fatigue, dryness, etc. over that snapshot of time since your last appointment. So if I could have that information beforehand, that's really great because then I can maximize my time with you on focusing on what has not been going well.

Dr. Dana Direnzo (00:15:55:03 - 00:17:07:00)
So, for example, if you're filling out like a wide variety of questions related to your quality of life, and then I scan and I'm like, “Okay, it looks like her fatigue has been really elevated and that's what she's marking off. I'm going to, from the get-go, start talking about your fatigue.” Because I know you've already communicated to me, yes written or, you know, questionnaire-based, but you've communicated these other aspects have seemly been okay. I'll check in with you, like, “Are you sure, you know, everything is going alright?” But for me, I want to focus on what you're marking down as to be the most interfering since your last appointment. The other thing that I really appreciate on the patient's behalf is, a lot of times, at least in a lot of city hospitals, people get their labs and maybe imaging done at a lot of different places. So I know I try to look it up like, okay, what have your labs been since the last time you've been there? Have you had any ultrasounds or image is done? But sometimes you might have gone to a different

radiologist or radiology facility. You might have gone to a different lab place. So also, you know, having your latest information on file, can be really important and valuable.

Dr. Dana Direnzo (00:17:07:06 - 00:18:27:19)
I actually, some of my long-standing patients have trained to know what I use to calculate how active their Sjögren's disease is, and particularly the questionnaires, the patient-reported outcomes, what I'm tracking over time. Because I want to empower them to be like, "Here's my information. How can we plan and work together to get this to where I want it to be?" So, for example, for Sjögren's, we track a lot the disease activity index, which is programed into our computer, at least in our clinic, but it is widely available. And then educating the patients. These are what I use as your doctor to make an informed, you know, calculation of how active I think your disease is. So I have some patients who will literally come in and say, "I want to talk about my fatigue. This is how I've been reading it. And my disease activity index is too." And I'm like, "Wow, you know exactly how you want to spend your time." So I appreciate that. So I appreciate an organized patient. However, that is not to discount if you do not have that done, and we need to like figure that out together. So if you are trying to prep for an appointment, ideally, you know what you've had done since the last time you've see me, and you know how you're feeling or what is interfering and what you want to focus on. But by no means does that have to happen. That would just be an ideal scenario.

Shilpa Venkatachalam (00:18:27:21 - 00:18:43:01)
Wonderful. And, you know, one of the things that we've heard often from the patient community is, "Well, do those questionnaires make a difference?" It's really validating and reassuring to hear you say that you do look at that when you're speaking.

Dr. Dana Direnzo (00:18:43:05 - 00:19:25:10)
Absolutely. Absolutely. That is the most important thing that I need. That is the number one thing I want to know. I want to know exactly what has been happening since the last time I've seen you, particularly because I know we're going to have a short amount of time together.

Shilpa Venkatachalam (00:19:25:12 - 00:19:38:09)
Wonderful. And Melissa, has that been your experience too before you go into an appointment? Do you have to fill out these questionnaires? Or, you know, you alluded to treating it like a meeting. So you're going in prepared.

Melissa Taylor (00:19:38:11 - 00:20:45:01)
Yeah, I go in prepared. I have not received these questionnaires typically beforehand. I think that would be really helpful for me as the patient. So I love that you're doing that. No, the way that I prepare, so for a long time I didn't know how to track my symptoms or what symptoms exactly I should track. Because I would, you know, bring in pictures and be like "My eye blew up like a balloon." And they'd be like, "Well, you know, what were the circumstances?" And I had forgotten. I don't know, I just thought this was, you know, the evidence. So a lot of the time, my tracking efforts were not, unfortunately, what was going to be helpful. But as the patient, I didn't really know what they're sort of looking for. So I think it's important to again, it comes back to communication because it's just a difference in how we're communicating together as doctor and

patient. So just knowing what is my doctor looking for? Do they want me to take my blood pressure in the morning or at night or both? Or, you know, what am I tracking exactly?

Shilpa Venkatachalam (00:20:45:03 - 00:20:53:18)
That's a great point, Dr. Direnzo, right, is to ask your doctor, “How can I help to make this appointment optimal for both of us?”

Dr. Dana Direnzo (00:20:53:20 - 00:21:53:23)
That's a very valid point. And I know your foundation has a lot of resources that kind of outline that kind of stuff. So, maybe you could tag that to be attached to the podcast. But I know I've had patients tell me it. Like I'm going on your website and everything like that. So I think it's really good to be organized. And then asking your doctor, “Hey, what do you want me to track? Or what type of information should I be looking for?” I actually get asked a lot by patients, “You always tell me and ask me all these different things. Like, what do you want me to tell you when I'm having a flare, if I think that I'm not doing well?” Which oftentimes is alluding to, you know, having in an abnormal range, some of these patient-reported outcomes, you know, the scoring for them. So I think that's useful. And sometimes I got to figure this out, you know, like prompting or triggering that you're filling this out for me or you're kind of to help you articulate to help you communicate, you know, like what symptoms are distressing or impacting or interfering to you.

Shilpa Venkatachalam (00:21:54:01 - 00:22:42:07)
Lovely. I think that's a tool I'm going to use as well with my rheumatologist. I want to talk a little bit about, you know, we live in an age of sometimes too much information. Sometimes information that's not reliable and evidence-based. But it's all there on the internet. And so I'm googling for rheumatoid arthritis, but in this case, Sjögren’s disease. How do I discern what is evidence-based versus, you know, what is just white noise, for example? Dr. Direnzo, I want to ask you this question first before I come to Melissa. Any tips on how we as patients can understand the difference between what is really reliable and what might not be so reliable?

Dr. Dana Direnzo (00:22:42:09 - 00:23:57:03)
I think it’s the type of information you're looking for. So certainly foundation resources, Global Healthy Living Foundation, Sjögren’s Foundation, American College of Rheumatology, those are the three sites that I really like for patient summaries and information regarding disease dates and educational material. So I would caution you, not that it might not be good information, but it might be less vetted coming from different sources. And then particularly, I want patients who are very interested in all the clinical trials coming up and then evidence behind some of the medications they might take. It's really hard to interpret journal articles sometimes if you don't have a medical background. But that's not to say that you can't send what you're trying to digest to your rheumatologist and say, I actually get this a lot, “Hey, can we go over this research study.” Or “Can you go over some of these papers of why you have me on certain things from what's coming out?” That might be a little bit lofty. But anyway, I would stick to those three, if you're getting started, to stick to those three bigger foundation websites.

Dr. Dana Direnzo (00:23:57:05 - 00:25:08:12)
And then it always comes up, but the use of AI like ChatGPT, you know, when you type in your symptoms, what comes back? I have to caution you on that. I have a lot of very, very distressed

patients over what ChatGPT tells them, because at the end of the day, you have to remember sometimes there's legality associated to it. So it's always going to end with you somehow going to the emergency room. So I just caution you, if you are, you know, having a lot of distress, just contact your doctor's office and talk them through that before you have the added stress of seeing what ChatGPT is going to tell you to do. I'm making a joke, but I'm not really because I do get snapshots of ChatGPT questions a lot throughout my day. So yeah, so I think sticking to the foundation websites, limited use sometimes of the AI, unless you're looking up very like science-based type of questions that can turn out like journal articles that you would digest, but, you know, a little bit of caution on that, and then the different types of- maybe we'll ask Melissa, I'm going to now jump in, I'm going to steal your- I'm going to ask Melissa a question.

Shilpa Venkatachalam (00:25:08:14 - 00:25:10:13)
Please do, please do.

Dr. Dana Direnzo (00:25:10:15 - 00:25:36:01)
So Melissa, tell us about how you find and get connected to patient blogs and that type of online community groups. Because I actually get a lot of patients reporting a lot of good things, but then I get a lot of distressing things too. So how do you find a good balance that's like a positive experience to you? So I'm just going to jump right in.

Shilpa Venkatachalam (00:25:36:03 - 00:25:39:05)
Love it. I love that question. Go ahead Melissa.

Melissa Taylor (00:25:39:07 - 00:25:41:08)
[Laughing] So, so-

Dr. Dana Direnzo (00:25:41:10 - 00:25:43:11)
[Laughing] Asking for myself. I'm asking for myself.

Melissa Taylor (00:25:43:15 - 00:26:36:07)
Yeah, yeah. Well for me I'm very, I think, very skeptical to begin with myself. So the things like Chat, you know, if I ask Chat a question, I'm going to immediately challenge its answer and say, "Well, is that actually true?" And a lot of the time it will come back and say, "Well, it's not totally true." And I'm like, "Okay, this is garbage. Let's just throw this out." So I don't even really, personally, I don't even really bother with that aspect of it because it's just a waste of my time. And it will lie to you confidently. So for me, like finding the online communities, I think I started on Reddit and there's a Sjögren's community on Reddit, and that's when I realized a lot of people are talking about like, "Hey, I have the same kind of symptoms that these people do. This is really cool."

Melissa Taylor (00:26:36:09 - 00:27:44:15)
And then I by chance got connected to, there is a physician in the community, her name is Dr. Kara Wada. She is, I think she's a board-certified allergist immunologist. Sorry Dr. Wada if I got that wrong. I think that's right, though. And she lives with Sjögren's herself. So I'll get a lot of helpful information from her directly, because she's actually a doctor and she lives with Sjögren's disease. So it's kind of like this perfect "ahh" moment when you find someone like her. And then

obviously, the Sjögren's Foundation, I trust that they're putting things out that are going to be accurate. And I found these resources, I believe I had started out on Reddit is where I found them, just by chance. So, that's usually what I follow along with. There is another community called Sjögren's Advocate. I will follow information on there, too. That's run by another physician, Dr. Sarah Schaefer. And she has Sjögren's, and I believe she had seronegative Sjögren's and had to go through a whole rigamarole to get her diagnosis. So I'll look for information on her website too.

Shilpa Venkatachalam (00:27:44:17 - 00:28:56:09)
Lovely. Yeah, there's a lot of support communities online. I turned to Creaky Joints myself when I was first getting diagnosed. And then, as you said, Dr. Direnzo, there's, you know, also the foundations, Sjögren's Foundation, Global Healthy Living Foundation, etc. There is also institutes like the NIH, etc. that you can trust are going to put through evidence-based information. But yeah, be a little wary I think is the message from the Dr. Chats and the Dr. Googles and the Dr., I don't know, Windows Explorer. Because who knows where they've graduated from. But to that end, you know, and Dr. Direnzo, you talked about clinical trials where you just touched upon it. And I want to talk, you know, as we're bringing this episode to a wrap, I want to look to the future a little bit with a little bit of optimism, I hope. And there is a lot happening in Sjögren's research and treatment. What are some developments or areas of research that give you the most hope for the future?

Dr. Dana Direnzo (00:28:56:11 - 00:29:56:15)
I am excited about it all. And I truly, truly mean that. I think with all the clinical trials from multiple different drug companies coming out, it's really put Sjögren's on the forefront of research. And so not only, you know, figuring out what drugs are going to work, which is fantastic, but also just basics about the disease. And certainly we have to understand the health-related quality of life and how impacts Sjögren's. So with all these clinical trials and all these pharmaceutical wonderful different initiatives, we're also understanding the disease itself. So I think it's accelerated Sjögren's research in a really good way. So I'm very excited that infrastructures are growing and put in place, that we can set up long term cohorts, and understand ways to track and manage Sjögren's disease. But then also, of course, I'm excited about the drugs to come out because it's a very difficult conversation to have when you don't have an FDA approved drug to go to when you're in these appointments.

Dr. Dana Direnzo (00:29:56:18 - 00:30:56:22)
So I kind of make this comment a lot when I'm talking about Sjögren's, but it's really hard. And it was harder back then. And now it's just, I'm very hopeful. To have a conversation where you're like, "Well, you know, I'll see you in a couple of months. We're going to track this and that. We don't have an exact, you know, way to treat or manage your Sjögren's disease. Just let me know if you have questions." That is a terrible way to end an appointment, I hate that. And now I'm just so excited that there are going to be drugs that are specific to the disease, that you know exactly what the trial data is, and that you're going to say like, "This is x, y, z reason why we're going to do these drugs, and I'm very excited, and we're going to treat your inflammation and hopefully prevent and decrease the amount of flares you're having and prevent a lot of comorbidity that comes down the road with that." So I'm wonderfully excited about every aspect that's going on with Sjögren's.

Shilpa Venkatachalam (00:32:28:19 - 00:32:54:14)
That's very, very interesting. Good learning for me as well. Melissa, I know you've been very excited and especially when you heard Dr. Direnzo talking about the future of this disease and the promise of, you know, or at least potential for better treatments, right, and the research that's happening in the field. Would you like to add anything to that note of optimism?

Melissa Taylor (00:32:54:16 - 00:34:00:12)
Yeah. I'm just, I'm over the freaking moon about it. I think like, for me, I understand, you know, that, I've come to understand over time, because I wasn't a science person, that, you know, the medical wheel turned slowly, and there's a really good reason for that. It needs to turn slowly so it can turn safely. And I understand that on a logical level, but on a human level where I'm struggling with a disease, I'm like, I don't have 100 years to wait. And so even just a few years ago, I was of the mindset, sort of, that maybe, I was just hopeful that maybe I'd see a treatment option in my lifetime. And so now, within the last year, two years, I'm starting to see all of these trials, all these medications are coming out, and I'm still young and I'm still feeling like, "Oh my God." Like this is going for me and a lot of patients, I think this is going to be life changing. And we are going to be able to recoup some of that identity that we have lost that we had talked about earlier. And yeah, I'm super excited about that.

Shilpa Venkatachalam (00:34:00:14 - 00:34:45:04)
Yes. And I think we all share that excitement and that hope and optimism. You know, and we should say thank you to everyone who helps to advance the science - clinicians, people who live with the disease, and the researchers behind the work as well. So on that very optimistic note, I'll ask one final question of you both. If someone who's listening to this episode of our podcast asks, you know, "What next?" What would you have them do as a next step after listening to this podcast? It's a pretty difficult question, but curious to hear your thoughts on it.

Dr. Dana Direnzo (00:34:45:06 - 00:35:26:01)
So I'll start. So if someone asked me, "What's next?" I would say, what should be on your plate is to find someone to partner with you to figure out what is going on with your experience. Do not be afraid to bring up anything, even if you perceive it to be small, bring that all up, small or large. So if you have a lot of symptoms that you heard us talking about throughout these podcasts, bring up Sjögren's as a possibility, ask to be tested for that. Because that definitely should be on the differential for every rheumatologist.

Shilpa Venkatachalam (00:35:26:03 - 00:35:30:13)
Lovely. And, Melissa, would you like to add something?

Melissa Taylor (00:35:30:15 - 00:35:46:23)
I think that really wraps it up really nicely. And I would say on a personal note, take a little vacation and celebrate that you've figured it out.

Shilpa Venkatachalam (00:35:47:01 - 00:36:02:02)
Lovely. Well, on that note, this was, again, another fascinating conversation. I wish we had more time to continue this conversation, because there's so many more things that we haven't had the chance to touch upon. But again, thank you both very much.