Dr. Shuvro Roy and Dr. Catherine Otten

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[00:00:02] **Krissy Dilger:** Welcome to the "Community Meets Clinic" series, a collaborative podcast to introduce the clinicians, clinician scientists, and healthcare personnel working directly with individuals and families facing a rare neuroimmune diagnosis. Hear directly from those in the clinic and connect with the individuals whose focus is promoting quality of life for those diagnosed with a rare neuroimmune disorder.

[00:00:28] SRNA is a non-profit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our web site at wearesrna.org. "Community Meets Clinic" is sponsored in part by Amgen; Alexion, AstraZeneca Rare Disease; UCB; and Genentech.

[00:00:52] My name is Krissy Dilger, and I moderated this episode. Today we meet Drs. Shuvro Roy and Catherine Otten. Dr. Roy is an assistant professor of neurology at the University of Washington, specializing in neuroimmunology with a specific focus on multiple sclerosis and related neuroimmunologic disorders. He is a co-director of the University of Washington, SRNA Center of Excellence for Rare Neuroimmune Disorders.

[00:01:21] Dr. Otten is a clinical associate professor of neurology at the University of Washington in the neurology department, specializing in child neurology and pediatric neuroinflammatory disorders. She is also the Neuroimmunology Medical Director at Seattle Children's Hospital where she runs subspecialty programs for patients with rare neuro immune conditions. You can view their full bios in the podcast description.

[00:01:48] Thank you so much for joining me today, Dr. Roy and Dr. Otten. I'm excited to be able to speak with you and learn a bit more about both of you as well as the clinic at the University of Washington. So, to start, can you each tell me a little bit about yourselves and what led you to neurology and in particular, neuroimmunology. Dr. Roy, let's start with you.

[00:02:13] **Dr. Shuvro Roy:** Sure, absolutely. Well, first of all, thanks. Thanks for having us on and for giving us the opportunity to highlight the work we're doing in our clinic. For me, I'm an assistant professor of neurology at University of Washington. And for me I think the answer is probably the same for both neurology and neuroimmunology.

[00:02:35] We can certainly have good days or bad days as a neurologist, but you're probably never gonna have a boring day. And for me, that was a big part of my decision. There's such a diversity of the conditions that we treat in neurology once I'm covering the inpatient service.

[00:02:54] And then certainly on in neuroimmunology. It's always really fun. For example, with some of the trainees who come through like, okay, yes, we're gonna see some patients with MS. But also next is a patient with autoimmune encephalitis. After that is a patient with MOG-AD. After that is a patient with neurosarcoidosis and there's a million things to be able to teach from there.

[00:03:17] And it's really exciting to be able to dive into that and then look into all of these different conditions. And so, for me it's just it's always a really stimulating experience.

[00:03:36] **Krissy Dilger:** Awesome. Thank you. And Dr. Otten.

[00:03:39] **Dr. Catherine Otten:** Thanks for inviting us. As Dr. Roy said, it's really a pleasure. So, I'm a pediatric neurologist and a neuro immunologist here at the University of Washington, and my clinical practice is based at Seattle Children's Hospital. And I may have a similar answer to Dr. Roy. I think both the immune system and the brain are just equally complex and fascinating. In college and medical school, I was first drawn into neuroscience research and then found that

[00:04:08] Well, that was a fascinating area. My advocacy work was also with children and families, and so I came to pediatric neurology kind of through dual interests of understanding the brain, but also in childhood development. The brain goes through such a transformation during childhood and pediatric neurologists get the privilege of caring for children from babies to adults.

[00:04:26] So we get to see it all, and I really love the opportunity to tailor care to patients depending on their age. For example, a lot of rare neuro immune conditions present differently depending on the age of the patient and their developmental stage. And so sometimes there's even different treatment options too.

[00:04:44] It was during residency though, that I got drawn to neuro immune disorders specifically. I mean, in part because as I mentioned, the immune system is so complex. And unique just like the neurologic system. But also in practice you get to work with families facing chronic disease and so you get to know a patient and their family so well, and I get to be there from their first diagnosis where the family may be trying to understand what it's going to mean for them and maybe trying to help the child with an age appropriate understanding of their condition.

[00:05:16] Because they're chronic conditions, I'm still with them throughout their childhood until I pass them to Dr. Roy, the provider, and I get to celebrate milestones with them like graduating high school. And I think working with families and patients who are facing chronic diseases, just so humbling, the resilience and strength and love that you see in a family when a child is facing a disease like that is just very inspiring.

[00:05:44] **Krissy Dilger:** Awesome. Well, thank you both so much for introducing yourselves and also for the work that you do. I know our community really benefits from passionate and dedicated professionals like yourselves. So, thank you so much for that. So. Next. Can you talk a little bit more about what led you to focus on the rare neuro immune disorders?

[00:06:09] I know we kind of talked about that in the last question, but also, do you have any particular interest areas that you are working on in your research? Dr. Otten, do you wanna start?

[00:06:21] **Dr. Catherine Otten:** Sure. I have a number of interests within neuro immune disorders because they are such an amazingly disparate group of conditions.

[00:06:31] I've been working with the CDC on acute flaccid myelitis research, helping with surveillance so that we can really track acute, excuse me, acute flaccid myelitis across the country and hopefully understand its pathophysiology or what causes it. I am, though, I would say at heart, a clinician, and my other passion is just providing the best clinical care we can to families facing rare immune conditions across our region.

[00:06:53] And I wanna make sure patients get evidence-based care with the current medical research supports is the best option for them but also individualized care depending on their role within their family, within their community. And that often means collaborating a lot with local pediatricians and health centers where families live to make sure they get as much treatment as they can close to home, even if their subspecialty care is with me. Keeping travel as concentrated as possible. I started our multidisciplinary clinics with that in mind.

[00:07:25] **Krissy Dilger:** That's awesome. Thank you so much for sharing. And Dr. Roy, do you wanna talk about your research and particularly the rare neuro immune disorders.

[00:07:37] **Dr. Shuvro Roy:** And, and I'm just gonna steal a little bit of Dr. Ottens answer in terms of how I ended up in the space is, is very much for the same reasons. For me, the immune system and the brain and the interplay between the two are so complicated even when I talk to some of my physician friends who are outside of neurology and I tell them I'm a neuroimmunologist, even they say, what is, that's a thing?

[00:08:08] And so being a part of that and, and getting a chance to be that companion for patients as they're going through these exceedingly rare conditions and being a part of their journey there are a number of patients that I've been fortunate enough to Dr.

[00:08:25] Otten has passed on to me and getting to be a part of seeing them grow up and navigate life and still reach their individual goals while dealing with these rather complex, often not fully understood conditions is remarkably rewarding.

[00:08:46] I mentioned research. I also mentioned a little bit about advocacy as well, just because we've done a previous recording on that. In terms of research, we're looking at a number of conditions and really just trying to build on the knowledge base especially when it comes to NMOSD,

[00:09:10] MOG antibody disease. We are building databases that we're collaborating with a number of institutions around the country to try to boost the numbers we have so that the information we can draw can help us fill in some of those gray areas. For example, with MOG antibody disease, how do we know or if patients are particularly at risk of a relapse down the line after their first attack.

[00:09:35] We're also working with a neurosarcoidosis consortium to look at things like certain biomarkers. Are there ways that we can diagnose patients faster and thus get them on treatment faster and avoid worse outcomes? So that's a little bit of what we're doing from a research standpoint and also looking at

[00:09:57] some of these newer immune therapies like immune checkpoint inhibitors that are used in cancer treatment and revolutionize that field but can lead to some autoimmune neurologic conditions. And then from an advocacy standpoint working with the consortium of MS centers to

[00:10:16] really help improve knowledge of these rare neuro immune diseases for providers who didn't go through, say, an autoimmune neurology fellowship or a neuroimmunology or MS Fellowship. And how can we make sure that we can help standardize the care of these patients whether they're fortunate enough to live in some coastal academic center or, you know further away from one of those institutions. So that's what we're working on at the moment.

[00:10:46] **Krissy Dilger:** That's awesome. A lot of great things in the works and we appreciate all the research and advocacy that our medical professional network does. And thank you so much for sharing about it. So, part of the purpose of this podcast is to kind of help you talk about and share about your clinic so that if

[00:11:13] people who are diagnosed with one of these disorders want to potentially switch to your clinic, they kind of get a feel for what it's like to do so, so would it, would you be able to share more about your specific multidisciplinary clinic teams. What other specialists might a new patient expect to see if they have an appointment with you?

[00:11:37] How does a new patient typically get connected with you and what might that look like? I know Dr. Otten you are based at Children's Seattle, so maybe you can talk about that. And Dr. Roy, if you'd like to talk about the University of Washington. Dr. Otten, do you wanna start?

[00:11:55] **Dr. Catherine Otten:** Sure, I can start. We'll start chronologically. Patients will typically see me at Seattle Children's Hospital. We are the largest pediatric specialty center in the state, and often families are traveling from long distances to be there. They may be meeting me through a referral from their local neurologist. They may be meeting me after a hospitalization at our center if they're experiencing their first event of their disease.

[00:12:22] They may be referred by their pediatrician and they're typically meeting me in clinic, although I do meet some patients in the hospital too. In my neuro immunology clinic, they're going to meet with me. They're going to meet with my nursing team, and they're going to meet with my neuropsychology colleague, Dr.

[00:12:38] Ashman too. And we try to coordinate visits for patients since they're often traveling from either across the state or from other states. So, they might also be getting a brain MRI, a spine MRI, having labs drawn, even getting infusion in our infusion center on the same day or the same trip. In my inflammatory brain disease clinic where I see patients with autoimmune encephalitis and other diseases associated with brain inflammation, I also partner with a rheumatologist as well and we actually physically see patients in the room together at the same time.

[00:13:12] And we found that this really helps keep the number of clinic visits down for my patients and their families but also helps with communication. When we're collaborating on a patient's care, it can be really key to have everybody together in the same room at the same time. And that way families aren't needing to be the messenger between different subspecialists, and they can really be part of the conversation that we're having about a child's complex care. So, it really does look very multidisciplinary when it comes to caring for families over here.

[00:13:44] **Krissy Dilger:** That's great. And I think a huge benefit of going to a center such as yours, is you do get that comprehensive care in one place and it kind of just eases the burden of having a new diagnosis and being overwhelmed. Having, a multidisciplinary team right at the clinic is just so helpful. And Dr. Roy, do you wanna share about University of Washington?

[00:14:10] **Dr. Shuvro Roy:** I, I feel quite spoiled constantly because of the team that we have in place at our center. And whereas Dr. Otten has certainly built this multi-disciplinary team, I got to very much just walk in, and we have a lot of this infrastructure in place, but it's also what drew me to University of Washington. So beyond, you know neurologists like myself,

[00:14:34] we have another collaborator who's a director of the Rare Neuroimmune Disorders Clinic, Dr. Wong, as well as our five other neuroimmunologists in our clinic. Really, I think what makes the clinic work is everyone else, for example, for folks receiving treatments, we have a dedicated group of infusion nurses who really get to know our patients and guide them through those treatments.

[00:15:08] We have nurses who are there answering messages, answering patient calls every single day, who have really learned so much. Not just about MS, but we also do didactics for them about the MS mimics and rare neuroinflammatory disorders that they're going to be asked questions about.

[00:15:28] We have two nurse practitioners who also are quite capable, especially of seeing patients with NMO MOG Antibody Disease. We have an outstanding neuro ophthalmologist, Dr. Eugene May, who takes care of many patients with optic neuritis, for example.

[00:15:48] But then I think where we really shine is some of the other folks is we have two rehabilitation medicine providers, Dr. Sarah Simmons, Dr. Gloria Ho, who really help guide patients through issues with symptom management, whether that may be mobility, whether that may be spasms, vision, fatigue. Bowel and bladder issues. They take remarkable care of our patients in that way. We also have a team of psychologists.

[00:16:16] And then on top of that I think we have two excellent individuals, one social worker Marie Kong to help patients with just, I feel like whenever we're not exactly sure what to do, we call Marie and ask, "Hey, can we find a solution?" We also have a vocational counselor, which I think is a really unique aspect of our clinic,

[00:16:39] Joe Stuckey, and his job is to help navigate patients through the processes of things like work and school accommodations, disability, these processes that are just remarkably complex and challenging to take on alone. Joe has been such a remarkable addition to our clinic and helping patients be able to navigate that in a way that's not completely overwhelming. So, it is very much a team effort.

[00:17:11] **Krissy Dilger:** Oh, that sounds amazing. And I think you're the first to mention a vocational think you said counselor. That's awesome. I think having all those resources in one place can be just so, such a relief. For people who are experiencing this diagnosis in a time of turmoil, it's kind of calming to have so many resources right there for you.

[00:17:37] So that's awesome. So, I can imagine as clinicians, especially when you're dealing with so much unknown with these disorders, as well as sometimes the severity of different cases can be different. That this can sometimes take an emotional toll. So how do you take care of yourselves and what do you do in your free time that helps you relax or reset? Dr. Roy, do you wanna start?

[00:18:08] **Dr. Shuvro Roy:** Oh man. So, I feel a little pressure for this question because Dr. Otten is also the head of our wellness committee. So, I feel like I really need to deliver a good answer here, and then I wish I had t the answer, but for me, I think that's something that I'm always trying to improve on or trying to be better about is, you mentioned that there's a lot of turmoil in just the world nowadays, and there's a quote I like where you say when the world turns the wrong way around, the best defense is community and ordinary.

[00:18:43] And so for me I think when I think about that in clinical care, I think a lot of that comes from okay, like I said, I am absolutely spoiled as a provider. We have six other Neuroimmunologists and, in our clinic, and also two nurse practitioners. And so, when I'm not sure of a question or if I'm trying to figure out what, how can we best care for a patient, oftentimes I'm turning to my internal community in that clinic.

[00:19:14] Oh my gosh, I forgot to mention our, we also have a Neuroimmunology pharmacist which I think is a huge addition to our clinic too. getting help from others or turning to others. And then in terms of just relaxing outside of that, I think, same sort of thing, making sure to find a time and make time for our community and

our routine. At the risk of being like a totally stereotypical person from Seattle, I can't do without my morning coffee routine. I just, I really find that if I don't have that in the morning, my day is very different. And so just little things like that or what, at least keep me relatively on track and, and make sure that hey, I can try to present the best version of myself for my patients.

[00:20:05] **Krissy Dilger:** Great. A fellow coffee person over here, I can totally relate. So that's great. Dr. Otten?

[00:20:14] **Dr. Catherine Otten:** Thanks for asking this question. We know from medical research now, a plethora of it, that caregivers and physicians alike need to find a way to take care of their own wellbeing in order to be there for those they care about. But it can be hard to prioritize. On my end, I'm also a stereotypical Pacific North Westerner, and I feel so lucky to live in Washington State where we have such wonderful outdoor spaces.

[00:20:38] So I would say I spend my free time with my family outside and usually that's hiking, or it could be camping or swimming. We have a map at home where we track as a family all of our hikes, and we have dozens on the map now. I think in particular, kind of the repetition and that slow upward progress of hiking in particular, I think it's really meditative for me personally.

[00:20:59] And it's an added bonus that exercise and time outdoors are great for physical help. But I feel really lucky to have such wonderful outdoor spaces that we can access pretty quickly. And as Dr. Roy said, there's really no way to say it, but community is incredibly important. And that's everything from having great family, great community and friends, but also great colleagues too, who really understand when you're facing a really tough challenge with a family, what everyone's going through.

[00:21:35] **Dr. Shuvro Roy:** I feel like I need to really learn from you where hiking becomes meditative because we just did like a trip out to the Olympic Peninsula. We did Mount Storm King and that was miserable. I feel like I need to get some pointers from you on how to make that a more relaxing endeavor.

[00:21:56] **Krissy Dilger:** That's awesome. Yeah. II had my first visit actually to Seattle earlier this year, and it really is beautiful. So having that landscape where you live and work is a huge benefit. So, is there anything that you would like to share for people with a rare neuroimmune disorder who are considering your clinic for care? Dr. Roy or Dr. Otten, either of you wanna take the lead on this one.

[00:22:29] **Dr. Shuvro Roy:** I can start. I would say for patients who are maybe either recently diagnosed or looking for care just know that you're not alone. What we take pride in in our clinic is for patients with these neuro immunologic conditions that we're sort of a one stop

[00:22:52] shop where maybe we can't address every single thing, but we try our hardest to come as close as we can. Whether that is symptom management, whether it is managing your neuro immunologic condition, providing even workshops for different aspects of the condition.

[00:23:14] Patient programs, even patient education days, we want you to be able to feel that, hey I'm not in this on my own. And, you know, that I do have a team who is here to help care for me. We may not have every answer, but we are certainly going to try to find every answer together.

[00:23:37] And certainly, as we continue this longitudinal or long-term patient provider relationship, we're gonna keep you updated every step of the way on what's going on and what all the many, many, many new, exciting developments are occurring in this space.

[00:23:56] **Krissy Dilger:** That's great. Dr. Otten, is there anything you'd like to share?

[00:24:00] **Dr. Catherine Otten:** Sure. I hope that any family considering our clinic at Seattle Children's knows that we want to be here for them for their treatment, but that we're also going to consider their care to be more than just their medicines. And I hope they know that our team is really invested in them and their future.

[00:24:15] We're starting at a much younger age, and we keep that in mind, and I hope they know that we're gonna be collaborating with a team with their family to consider the best options for them. And the best way to make that happen, whether that's in rural Alaska where I have outreach clinics or whether that's in metropolitan Seattle, and that might mean everything from setting up coordinated visits to reduce travel, to thinking about how disease is going to affect their education at school or whether life at home to making that transition with them when they reach adulthood to their next team.

[00:24:49] **Krissy Dilger:** Awesome. That sounds great. And so, we're coming to the end of my questions, but I do like to end on kind of a positive note always. So, I always try to ask this question. What are you hopeful for in the future of rare neuro immune disorders? Dr. Otten, do you wanna start?

[00:25:10] **Dr. Catherine Otten:** Absolutely. I think for pediatric patients, the future is really promising. The decade plus that I've been caring for patients in our neuroimmunology clinic, we just have so many more options to offer younger patients. We have more information about their effectiveness and safety in their age range. We have more treatments now than ever, and we have more clinical research trials that support their use.

[00:25:33] But on top of that, we just have better real-world experience to help us inform families when they're making a decision about their care. And for my families. Our patients are diagnosed so early in life, so having a really effective therapy early on just absolutely changes the trajectory of disability progression. And we are thinking decades ahead for pediatric patients. So, I think this has been a phenomenal development and I'm really optimistic about what the future holds.

[00:26:04] **Krissy Dilger:** Great. Thank you for sharing. And Dr. Roy?

[00:26:08] **Dr. Shuvro Roy:** For me, I think it's the overall expansion of really this entire field. A few years ago, the idea that you could have an autoimmune neurology fellowship as opposed to an MS fellowship was totally not an option. Now we're seeing more and more of those pop up. We are seeing more and more different pharmaceutical companies enter into this space, and that's really exciting. The idea that, oh, we could have FDA-approved treatments for not just autoimmune encephalitis, but specific types of autoimmune encephalitis, different FDA-approved treatments for MOG antibody disease.

[00:26:50] Certainly we look at, even five years ago, we did not have FDA-approved treatments for neuromyelitis optica. Now we have four. It's a really remarkable time. And just the idea of this expansion of this armamentarium and as Dr. Otten said, being able to provide patients, "Hey, here's a blueprint for—Yes, here's what your diagnosis is, and we can help you understand what that looks like, but also we can provide you a really, excellent long-term trajectory because of the treatments available to us now." That's just a really exciting and really beautiful thing to be able to share with patients.

[00:27:35] **Krissy Dilger:** Great. That sounds amazing. And I look forward to seeing what the future holds for this community. I think it's, I'm optimistic as well. So much has changed in the years since I've joined the community. When I started with SRNA eight years ago, and I can't imagine what it'll be like in eight more

years. So. Thank you both so much for sharing and for joining me today. I really appreciate your time, and I hope to talk to you again on another episode of one of our podcasts.

[00:28:08] **Dr. Catherine Otten:** Absolutely. It's really a privilege to get to work with you all, the SRNA. I know my patients and their families really appreciate the work that you do. Thank you,

[00:28:16] **Dr. Shuvro Roy:** Absolutely. I think there are countless resources I feel like I've shared with my patients, whether they're some of these patients who are non-English speaking or just many of the different guides on just helping understand what these diagnoses have been a tremendous help to many of my patients as well.

[00:28:37] **Krissy Dilger:** Well, thank you so much. That means a lot. And we're always happy to partner with organizations and centers such as yourselves, who do great work, and the collaboration really, I think, makes the best out of everything. We hope to continue.

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