

## **Dr. Monica Diaz**

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[00:00:02] **Krissy Dilger:** Welcome to the "Community Meets Clinic" series, a collaborative podcast to introduce clinicians, clinician scientists, and health care personnel working directly with individuals and families facing a rare neuro immune 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.

[00:00:29] SRNA is a nonprofit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our website at <u>wearesrna.org</u>. "Community Meets Clinic" is sponsored in part by Amgen; Alexion, AstraZeneca Rare Disease; and Genentech.

[00:00:50] My name is Krissy Dilger, and I moderated this episode. Today, we meet Dr. Monica Diaz, a clinician from University of North Carolina Health. Dr. Diaz is an assistant professor of multiple sclerosis and neuroimmunology at the UNC School of Medicine. You can view her full bio in the podcast description.

[00:01:12] Welcome, and thank you so much for joining me today, Dr. Diaz. I'm excited to speak with you and to learn a bit more about you as well as the clinic at University of North Carolina at Chapel Hill. So, to start, can you tell me a little bit about yourself and what led you to neurology and in particular neuroimmunology?

[00:01:36] **Dr. Monica Diaz:** Sure. So, first of all, thank you for inviting me to be on the podcast. So, my name is Monica Diaz. I'm a neurologist and neuroimmunologist at the University of North Carolina at Chapel Hill. And I've always been interested in the brain ever since I was young. I was always really interested in how mysterious the brain is and how it can really affect how we function, how we think, how we act. And then that also -- so that's what initially led me to go into neurology was just I was really fascinated by how it is that one small change in the brain can really have such an impact on people's lives.

[00:02:25] And then, I decided to go into neuroimmunology specifically because I was always really interested in solving problems. So, a lot of neurologic conditions sometimes we don't find an answer. We don't find a reason why it happened. But I like those maybe more uncommon neuroimmunologic disorders that really take more thinking and thinking outside the box. And there's a lot of thinking outside the box that happens in neuroimmunology.

[00:03:01] So all of that made me go into neuroimmunology, and I think it's a changing field. There are so many more treatments that are effective for many neuroimmunologic conditions that weren't available years ago. And it's definitely a changing field. So that's what makes it an exciting field to work in.

[00:03:26] **Krissy Dilger:** Great. And you already touched on this a bit, but what led you to be interested in particular in the rare neuroimmune disorders? So, some of these disorders that we advocate for at SRNA



such as transverse myelitis, neuromyelitis, optica spectrum disorder, MOG antibody disease and so forth. And then do you have any particular interest areas that you are working on in research?

[00:03:56] **Dr. Monica Diaz:** Yes. So those are great questions. So, like I mentioned, I went into -- I became interested in rare and immunologic disorders because I think it does take a lot of problem-solving skills sometimes to figure out what the diagnosis is because as you mentioned, these are rare conditions that oftentimes we don't even learn about in medical school. So, it does take a lot of thinking.

[00:04:25] And then I also really like the multidisciplinary approach. Sometimes we have to work with our ophthalmologists and urologists and rheumatologists to manage and treat patients well. And then as far as research, I do have a lot of research interests but right now my research focuses on demyelinating disorders in Latin America and also in ethnic minority populations in the United States. So, I have one research study where we're looking at the various etiologies or the various causes of transverse myelitis that occurs in Peru.

[00:05:13] A lot of my research is actually in Peru. I've been working there since 2019 on different projects. But I do have one study going on right now that is enrolling patients that are admitted with a diagnosis of transverse myelitis to a big neurologic hospital down in Lima and Peru.

[00:05:33] What we're interested in is looking at characterizing the different causes, so whether it's more infectious or autoimmune causes or other causes of transverse myelitis. And we're hoping to be able to get more participants and also analyze the spinal fluid. And there's a lot of information that we can gain from that spinal fluid including whether it's an infectious cause, an autoimmune cause or another cause. So, I'm looking at that.

[00:06:02] And then also very interested in how these conditions of both transverse myelitis, neuromyelitis optica spectrum disorder and MOGAD present in the Latino community in the United States. So right now, we're working on a study at UNC-Chapel Hill looking at how outcomes present in this particular ethnic population. And then also looking at, for example, health care access, health care literacy, distance from the patient's home to our facility and how that impacts clinical outcomes. So, relapses, disability and MRI activity.

[00:06:56] **Krissy Dilger:** Wow. That's all very exciting and important work. I know we at SRNA are lucky to work with such amazing researchers and clinicians such as yourself. And so, I think there's a lot to learn and thank you for doing this work. It brings a lot of hope to the community. So, can you share more about your specific neuroimmunology clinic team at UNC? What other specialists might a new patient expect to see if they make an appointment with you? How does a new patient typically get connected with your clinic and what might that look like?

[00:07:39] **Dr. Monica Diaz:** Yes. So, thank you for bringing up the clinic that we have. So, at UNC-Chapel Hill, we have The Bodford Family Transverse Myelitis Center, which is located in Hillsborough, North Carolina. It's just a short 15- minute drive from Chapel Hill, so right by the Triangle Area in North Carolina. And it truly is a multidisciplinary team because we have a wide array of specialists that we work with. So not only is it a neurologist that you will see but patients oftentimes will also be referred to our physical medicine and rehabilitation doctor that works with us in our clinic.

[00:08:22] Particularly, people that might be using a wheelchair or might need Botox injections for spasticity in their lower -- in their arms or their legs. We tend to work really closely with our Physical Medicine and Rehabilitation or PMR doctor. We also collaborate with a urologist, if patients have difficulty with bladder symptoms, a neuro- ophthalmologist, if they have difficulty with their vision. And then we also have nurses



that are trained in demyelinating disorders or in rare neuroimmune disorders that work in our clinic and a social worker and mental health therapist. And we also have a pharmacist as well who's key in really making sure that patients get started on their treatments very quickly.

[00:09:14] So, we truly are a multidisciplinary team and very collaborative in that. That's the nice thing about having all of these specialists all under one roof is that we can all talk to each other very easily. So not all patients need to see all of these specialists. It just depends on what's going on in their particular situation, but these are the specialists that are available.

[00:09:39] And the other question was, how does a new patient typically get connected with you? So, the referral process usually, it could be either a referral from a primary care doctor in the community or I would say more often than not it's a neurologist in the community. Our catchment area is very large. We see patients from all over North Carolina because we're the only transverse myelitis center in North Carolina. We have patients that come from Virginia, from Tennessee, from South Carolina. So, we get all of these referrals from the area. And it's really nice to be able to see patients coming from all over. So, it's good.

[00:10:25] **Krissy Dilger:** Sounds like a very multidisciplinary approach, which is always amazing, especially for patients to have that like a united front to handle all the things that can unfortunately come with being diagnosed with one of these disorders. So that sounds awesome. And we will link to your website in the description, so if anyone's interested in making an appointment, you can find that or you can search for Monica Diaz. And she is also in our medical professional network on our website. So that's great.

[00:11:08] So just as more personal question, I suppose as a clinician I know it can be heavy and there can be a lot of emotions when dealing with some of the incredibly difficult things that come with these disorders. So how do you take care of yourself outside of the clinic? How do you stay grounded? How do you reenergize after one of those tough days or weeks? And how do you spend your free time to do so?

[00:11:48] **Dr. Monica Diaz:** No. This is maybe the most important question. No. So I think it's important to realize someone's limit and just being self-aware in that you can't do it all. And I think it's especially important to take time to not just work all the time but take personal time and be with family, which is very important to me of course. And then also just doing things that are enjoyable outside of the clinic and outside of work time.

[00:12:26] So I have the fortune to live in North Carolina where we have a lot of great hiking trails, and I love the outdoors. So, my family and I will often do a lot of hikes around North Carolina, and a lot of traveling too. It's nice to go on road trips too, which is nice. So, those are some of the things that I enjoy doing outside of work and I think I especially love the outdoors because you can really take time to think about things and process things if needed. So that's my method, I would say. But – so, I don't know if that answers your question.

[00:13:10] **Krissy Dilger:** Yes. Yes, that's great. I think I'm a little jealous of the weather in North Carolina having been living further North. No, that's great. So, is there anything you would like to share for people? Someone diagnosed with a rare neuroimmune disorder who is considering your clinic for care? Anything you want them to know?

[00:13:37] **Dr. Monica Diaz:** Yes. So, I will say, — I didn't mention this earlier, but we see — I know the title of the clinic is a transverse myelitis center, but we see any patient with any spinal cord disorder. So that could be somebody with multiple sclerosis that's affected the spinal cord, transverse myelitis, neuromyelitis optica, any or an infectious cause. These are the major reasons why we — or spinal cord stroke. Those are the major reasons why we see patients in our clinic.



[00:14:12] So I think anybody that might be considering receiving care in our clinic could ask their doctor, their primary care doctor or their neurologist for a referral to our center and we're happy to see them. And then I think it's important to also just remember that it is – sometimes it can be a long recovery process. And one of the key things is really staying active. So, working with physical therapy, just making sure that you stay as active as possible to help with the recovery process after having had transverse myelitis.

[00:14:51] And then working with the multidisciplinary care team, whether that's the physical medicine doctor, the urologist or any of those other specialists that I mentioned earlier. And I think that really helps go a long way, and when recovering or when trying to maintain a certain level of physical activity and independence.

[00:15:20] **Krissy Dilger:** And my last question is just something I like to sometimes end my conversations with because I think it's important to stay hopeful. So, what are you hopeful for in the future of rare neuroimmune disorders?

[00:15:36] **Dr. Monica Diaz:** So, like I mentioned at the beginning, I think it's a really exciting field because there are so many treatments coming down the pipeline and effective, very effective treatments that weren't available even five years ago. So I'm very hopeful that in the future, one, we'll be able to find a cure for these rare neuroimmune disorders, but also if before we find a cure, if we can't find it that quickly, that we have more effective treatments with less side effects for our patients that will hopefully help reduce disability progression and relapses and those kinds of things that we monitor as clinicians.

[00:16:23] **Krissy Dilger:** Well, great. Thank you so much for joining me. That's the end of my questions. Hope to speak with you again, hopefully in another podcast in the future or at one of our events. And it was lovely getting to know you and hear more from you.

[00:16:42] **Dr. Monica Diaz:** Thank you so much for inviting me.

[00:16:46] **Krissy Dilger:** Thank you to our "Community Meets Clinic" sponsors, Amgen; Alexion, AstraZeneca Rare Disease; and Genentech. Amgen is focused on the discovery, development, and commercialization of medicines that address critical needs for people impacted by rare autoimmune and severe inflammatory diseases. They apply scientific expertise and courage to bring clinically meaningful therapies to patients. Amgen believes science and compassion must work together to transform lives.

[00:17:20] Alexion, AstraZeneca Rare Disease is a global biopharmaceutical company focused on serving patients with severe and rare disorders through the innovation, development, and commercialization of life transforming therapeutic products. Their goal is to deliver medical breakthroughs where none currently exist and they are committed to ensuring that patient perspective and community engagement are always at the forefront of their work.

[00:17:47] Founded more than 40 years ago, Genentech is a leading biotechnology company that discovers, develops, manufactures, and commercializes medicines to treat patients with serious and life-threatening medical conditions. The company, a member of the Roche Group has headquarters in South San Francisco, California. For additional information about the company please visit www.gene.com.