Drs. Grace Gombolay and Varun Kannan

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[00:00:00] **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 website 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. I would like to introduce our guests for today's episode, Dr. Grace Gombolay and Dr. Varun Kannan. Dr. Gombolay is an Associate Professor at Emory University and Director of the Pediatric Neuroimmunology and Multiple Sclerosis Clinic at Children's Healthcare of Atlanta.

[00:01:14] Dr. Kannan is an Assistant Professor of Pediatrics and Associate Program Director of the Pediatric Neurology Residency at Emory University and Children's Healthcare of Atlanta. You can view their full bios in the podcast description. Thank you so much for joining me today, Dr. Gombolay and Dr. Kannan.

[00:01:34] I am excited to be able to speak with you and to learn a bit more about you as well as the clinic at Emory University and Children's Healthcare of Atlanta. So, to start, can you each tell me a little bit about yourselves and what led you to neurology and, in particular, neuroimmunology? Dr. Gombolay, let's start with you.

[00:01:56] **Dr. Grace Gombolay:** Thank you so much Krissy and thank you so much to you and the SRNA for having us on this podcast. We're really excited to talk about the work that we're doing, including our clinic and everything happening at Children's Healthcare of Atlanta, which I'll refer to as "Children's" from here on out.

[00:02:11] So yeah, about me: born and raised in Texas and then moved up to schooling in Baltimore. Did all my training in Boston and then came down here. This was actually my first position after my fellowship training. And was really fortunate to be able to start the program here for taking care of—focused on children with rare neuroimmune disorders.

[00:02:35] I got interested in neurology because I've always found the brain really interesting and fascinating, and I've always really loved working with children and their families. And so that kind of made sense to me of going into pediatric neurology, because that's my primary focus of interest. And then I got into neuroimmunology actually when I was in college.

[00:02:55] So I happened to be volunteering for the partner for one of my professors, actually. And she is someone who is living with MS. So that's how I got interested in hearing more about Multiple Sclerosis, or MS. And then when I did my fellowship, I started learning about all of these other rare neuroimmune disorders that were also really interesting.

[00:03:20] And I've also found the immune system fascinating too. We only had two weeks in medical school, so that was my main exposure. So, it's been really interesting to see how my career has been built upon how the immune system affects the brain.

[00:03:37] **Krissy Dilger:** Great. And Dr. Kannan, can you also tell us a little bit about how you got into neurology and neuroimmunology?

[00:03:44] **Dr. Varun Kannan:** Of course. Yeah. I was interested in brain and behavior as early as college, and I was a neuroscience minor, and I got a certificate of extra courses in neuroscience. So, neurology was always on the radar when I started medical school. I initially was leaning more towards adult neurology, and then when I did pediatric neurology rotations, I was just having fun going to work every day, which felt like a good fit.

[00:04:11] I initially wasn't thinking about neuroimmunology. I had explored fields like neurogenetics and neurocritical care. But when I started doing residency, especially in my later years, I was just floored by how a targeted medication could change a kid's life.

[00:04:26] And we took kids from the brink in the ICU to going back to school, applying to college, playing sports; and the fact that we could utilize a frontier of medicine like immunology to change a kid's neurological wellbeing was... There's nothing else like it. So, I stayed; I did my training at Texas Children's and Baylor College of Medicine for residency and fellowship, and this is my first job out of training. And Dr. Gombolay pitched a really great gig here and I've been so fortunate to work with her as a friend and mentor. And I've been here for three years now.

[00:05:02] **Krissy Dilger:** That's amazing. Sounds like you found your calling. Dr. Kannan, what led you to focus on the rare neuroimmune disorders specifically, and do you have any particular interest areas that you're working on in research?

[00:05:18] **Dr. Varun Kannan:** Yeah. When you are a trainee and you meet these families, you're learning together. These rare diseases are new. For example, MOG antibody disease, we've known about for a couple decades now, but we've had clinical testing available to us since 2017. 2017 was my intern year. So, I feel like our field has learned about this disease as I've gone through my medical training.

[00:05:42] When I was first meeting families, they would ask, "What is this? What are we doing about it?" I didn't know the answers and a lot of my colleagues didn't either. So, we were digging into what research existed and realizing there's a lot of gaps. And I wanted to help fill those gaps.

[00:05:56] So some of the stuff I worked on during training was: there's some really severe forms of this disorder and there's some less severe forms. What makes those kids different? How do we tailor our treatment approach for both symptoms and disease management for these really rare, severe diseases?

[00:06:12] Dr. Gombolay's done an amazing job building a research infrastructure here at Children's and Emory, and I'm mostly focusing on helping connect the clinical pieces to her research infrastructure. We're working on some clinical trials as well that are really exciting. As a lot of people know, most of these diseases don't have approved treatments yet, and we're hoping that changes in the very near future.

[00:06:35] **Krissy Dilger:** Amazing. Thank you. And Dr. Gombolay?

[00:06:39] **Dr. Grace Gombolay:** Yes. My primary focus has been biomarker development. And biomarker is a hot topic. And people ask, "What is a biomarker?" And a biomarker is some sort of test, some sort of signal you have that can help you decide something. And that sounds vague, but there are different types of biomarkers including, for example, diagnosis or disease biomarkers.

[00:07:01] The MOG antibody like Dr. Kannan referred to, that's helping us with diagnosis, or the aquaporin-4 in terms of antibodies for neuromyelitis optica spectrum disorder. But there are other types of biomarkers that I've been really interested in, everything from prognostic— So, is there a biomarker that tells me how to predict a patient and how they're going to do in the future?

[00:07:23] Or is there a biomarker specifically to guide treatments? Is there a certain way that I can do this test that says, "Hey, you have this in your blood, your spinal fluid, or on your MRI, and this will help guide your treatment"? Because the ultimate goal is early diagnosis, preventing these diseases, what's the right treatment for these diseases, and ultimately cures for them.

[00:07:46] And so that's where I've based a lot of my research interest. And so based upon that, we actually have set up a biobank at Children's, that includes collecting specimens from our generous patients and families where they donate a little bit of extra blood or spinal fluid.

[00:08:09] They allow us to have access to their MRIs and their data too, so that we can start compiling all this data together to start looking at those aspects. And so, I've been doing some work in the lab looking at whether there are certain proteins or other things in that blood or spinal fluid that can help predict, again, outcomes or treatments.

[00:08:27] In addition to that, we've been working with a couple of neuroradiologists who are both at Children's and at Emory to identify if there are newer MRI techniques. And so, MRIs, as a lot of people are aware, are special pictures of the brain, and so there's certain sequences, certain types of MRIs that are currently done at most places if they do an MRI.

[00:08:51] And so what we've been working on with our neuroradiology colleagues is whether there are some extra sequences, other types of MRIs that we could do that could give us additional information that helps us, again, with maybe earlier diagnosis, better treatments, or better assessment of how a patient is going to do in the future or not.

[00:09:15] And so that's a lot of the things I've been working on internally at Emory and Children's. In addition to that, we have partnered with other organizations and other groups, including the Network of Pediatric MS Centers, which was initially started as an MS registry, but does also include other rare neuroimmune disorders.

[00:09:36] So it includes MOGAD, like we talked about earlier, NMOSD
[neuromyelitis optica spectrum disorder], optic neuritis, ADEM
[or acute disseminated encephalomyelitis], transverse myelitis, and other related diseases. And so that network has been in existence for over 15 years. There are 12 main centers that are part of the network that all contribute data. And so, we've been very fortunate that we get to be part of that effort to really pool everybody's experiences together. And so that's some of the work that we've been doing.

[00:10:09] **Krissy Dilger:** Wow, that is really interesting and really amazing. I look forward to seeing the research developments that come out in the next few years and few decades. Sounds like you're doing great

work. We at SRNA are proud to have Emory University and Children's Healthcare of Atlanta as Designated Centers of Excellence in rare neuroimmune disorders. We'd like if you could share a bit about your specific neuroimmunology multidisciplinary clinic team.

[00:10:42] What specialists might a new patient expect to see if they have an appointment with you? How does a new patient typically get connected with your clinic and what might that look like?

[00:10:58] **Dr. Varun Kannan:** Sure, I can take this one. Most of our new patients we meet in the hospital setting as a new diagnosis, having their first flare-up or exacerbation that leads to the diagnosis, and once they're stabilized and once we get them on the road to healing and rehabilitation, we set them up to establish their long-term care with us in our clinic.

[00:11:18] There are four doctors that work in our clinic: Dr. Gombolay, myself, and two other neuroimmunologists. I think the glue of our clinic team is our nurse coordinator, Gwen. Gwen basically becomes the go-to person for our families when they need to arrange their treatments.

[00:11:37] A lot of these diseases involve pretty intensive treatments with IV therapies. Some of them are done in the hospital infusion center, but Gwen has also been a great advocate for getting some of these done in the home setting through home health companies. Georgia's a big state. Travel can be really challenging and a barrier for a lot of our children and families to get the care that they need.

[00:11:55] So bringing the care to them has been a passion project of hers that I think has been really special and really successful. We also work closely with a neuropsychologist that helps, especially in pediatrics. One of our barometers of how well a child's doing is school performance.

[00:12:12] Trying to get them back into the flow of learning and development is really key. And a neuropsychologist helps to give us very specific ways that the school, teachers, and therapists can help our children get better.

[00:12:29] **Dr. Grace Gombolay:** Yes. And then in addition to that, we have access to a multitude of specialists, including if a child does need therapy, physical therapy, occupational therapy, and speech therapy, which includes cognitive therapy. We actually have a very extensive, specialized inpatient rehabilitation program specifically for children with neurological injuries or issues that also has wide access to resources.

[00:13:00] In addition to that, we work closely with our rehabilitation physicians or our physiatrists. We also have access to urologists if that's a need, and pain specialists, because sometimes pain can be an issue in our children who are living with these disorders. And then we also have access to our behavioral mental health center, which includes psychiatry and psychologists, so therapists for mental health.

[00:13:29] **Krissy Dilger:** That sounds amazing and comprehensive. Someone would get excellent care in your service. Thank you so much for sharing and spelling out what an experience at your clinic would look like.

[00:13:44] I can imagine as a clinician, especially when you're dealing with so much unknown with these disorders as well as the difficulties that some of your patients might face, that it can be hard for you. So how do you take care of yourselves emotionally? What do you do in your free time that helps you relax or reset? Dr. Gombolay, do you want to start?

[00:14:09] **Dr. Grace Gombolay:** I do believe that self-care is important because I know that when I am not in a good place, I can't help take care of the people around me. So, things I really enjoy include spending time with my family.

[00:14:24] I have a spouse and I also have children, so I really enjoy spending time with them and spending time with other friends. I really appreciate my colleagues, both at work and outside of work, whom I can vent to or commiserate with and also find solutions together. Sleep. I also find sleep really important and I think sleep is underrated, especially in this culture where we have access to all of these technologies.

[00:14:51] And most recently I've actually been trying to take a break from technology, including smartphones, laptops, TV, what have you, because I find that helps me in terms of my mental health and my wellbeing. And just things like being outside in nature, taking walks, going outside, taking trips, including to the beach. Those are the things that help me.

[00:15:16] **Krissy Dilger:** Great. Thank you for sharing. And Dr. Kannan?

[00:15:20] **Dr. Varun Kannan:** I think similar to Dr. Gombolay, I find a lot of comfort from spending time with my family. My wife also works at Children's, so different specialty, we are able to commiserate with each other. We have a dog and we have a 10-month-old daughter, so that is keeping us very busy.

[00:15:40] And one of the benefits of living in Atlanta is it's basically outdoor weather year-round. I am not very good at running, but I do like to get out there and try, and it feels good to sweat out the troubles of the day. I enjoy food. I enjoy cooking. Weirdly, after a busy, stressful day at work, I actually like to cook a really elaborate meal as a way to refocus my mind and still be engaged in something that's creative and tasty.

[00:16:08] **Krissy Dilger:** Great. That sounds good. I hope to get the invite one day.

[00:16:12] **Dr. Varun Kannan:** Yep. Anytime.

[00:16:15] **Krissy Dilger:** So, is there anything that you would like to share for people with these disorders who are considering your clinic for care, either one of you?

[00:16:27] **Dr. Grace Gombolay:** I can start. I think what I would really like to highlight—Dr. Kannan did mention how important Gwen our nurse manager coordinator is—but she has really helped benefit the children and families who come to Children's for care: navigating these diagnoses, navigating the healthcare system with the treatments and the appointments.

[00:16:55] What happens when an insurance denies a treatment? Unfortunately, that happens more frequently than we would like. Gwen is there. Gwen helps support families. She will call them. She'll keep them updated. She has... we've worked together to create all of these appeal letters, and she even has special numbers to certain places and certain insurance companies to really expedite the process.

[00:17:24] She knows the tricks; she knows the keywords that are needed to get those approvals done. And she really has gone above and beyond, like Dr. Kannan mentioned earlier, in how we help the children and families who need care, including keeping track of whether they are due for an appointment or due for their infusion.

[00:17:48] Is there a transportation issue? Then she'll work with our social workers to figure out transportation. We also offer financial support through our social workers, helping provide other resources we can access that are available in the community to the patients. She even helps with access to treatments from our home infusion company.

[00:18:15] So the home infusion companies will actually come to the house to provide the infusions for the patients and families. And that helps in terms of scheduling and in terms of not having to battle traffic. And

then for those who do want to come to Children's for their infusions, Children's recently opened up a beautiful new hospital that's state-of-the-art with lots of technology.

[00:18:42] And then the infusion center is on one of the higher floors and everything is glass windows and you can see the view of the city, of all the different Atlanta skylines. You can actually see Stone Mountain from there. It is just a really beautiful place, and we're trying to provide a place for healing for patients and families. And so those are a lot of resources that we can provide for those who end up coming to Children's.

[00:19:09] **Krissy Dilger:** That...

[00:19:09] **Dr. Varun Kannan:** Yeah. I'll...

[00:19:10] **Krissy Dilger:** Go ahead. Sorry.

[00:19:12] **Dr. Varun Kannan:** Sorry. Yeah, I was just going to echo and say the facility that Children's has created has been phenomenal. No child wants to be in the hospital, but I think we've done a good job in making that hospital environment as welcoming and as close to a place of healing as it can possibly be, and we're constantly trying to evolve that.

[00:19:31] But I think something that I'm proud of in our program is that we have a lot of resources in our physical space, but life doesn't happen there. We want our children and families to be comfortable managing what they're dealing with as far as healthcare at home. And I think home infusions is one example of that.

[00:19:49] We're also trying to expand our telemedicine capabilities so that, yes, we want to see our kids and families in person once in a while, but in between, especially if things are going well and it's a routine visit, let's make it as convenient as possible and utilize the technology that we have to make this convenient and less of a burden as we can.

[00:20:11] And really, we want our kids to feel like once they're on the right track of treatment and we establish a diagnosis, that this shouldn't be a barrier to live your life. And we want them to go to school. We want them to play sports, and we want them to do work and do all the things that they had planned to do. And we are there to help them along the way.

[00:20:30] **Krissy Dilger:** Thank you so much for sharing those perspectives, and it sounds like an amazing program you have going. I'm glad you were able to talk about it. I always like to end our podcast on a positive note. So, I'd like to ask, what are you hopeful for in the future of rare neuroimmune disorders? Dr. Kannan, if you'd like to start?

[00:20:56] **Dr. Varun Kannan:** As I hinted at a little bit, we are in the era now where there are a lot of clinical trials expanding. Again, for almost all of the diseases that we're trying to fight, we do not have approved therapies, but we really feel like in the next couple of years that's going to rapidly change. We have industry partnerships that are helping get these trials up and running. And it's a really exciting time.

[00:21:20] I think beyond that, we still want to do more. A lot of these treatments are focused on controlling inflammation and new disease activity, but the end goal, of course, is cures and ways to heal the damage that has occurred. So, a term that is very popular and growing is "remyelination."

[00:21:40] So for diseases where brain damage occurs that affects white matter and connectivity, we still don't have treatments that can directly heal that. And we're trying to get better at that. And I think that's the

next huge step that our field needs to take: find ways to not only control disease, but to reverse disease and get quality of life back to as high as we can.

[00:22:04] **Krissy Dilger:** Thank you for sharing. Dr. Gombolay?

[00:22:08] **Dr. Grace Gombolay:** Yeah, I just echo what Dr. Kannan said. I think that's where the field is going. One thing that I've been really excited to see is how the community has come together to approach the research and care in rare neuroimmune disorders where we have patient advocacy groups like the SRNA and other groups.

[00:22:30] We also have patients and families who are coming together. We have researchers, doctors, scientists who are really putting their heads together because everybody's important and everybody needs a seat at the table to understand how to best approach research in these diseases.

[00:22:45] So it's been really exciting to see all of these networks and organizations coming together to work together as a whole. Because that's how it's going to go. And then one of the other things, in addition to what Dr. Kannan said, is that what I would love to do is go also in terms of prevention. Is there a way that we could prevent these diseases from happening in the first place?

[00:23:08] And finally, we know we talk about artificial intelligence and machine learning really starting to be incorporated even into our daily activities and daily lives. But one of the things I would also love to see is: is there some sort of machine learning algorithm that we could create for earlier diagnosis?

[00:23:24] Because, unfortunately, for a lot of the children and families that we have seen, it sometimes takes some time before they reach their diagnosis to be able to get their treatment. But could there be some sort of machine learning AI prompt that when a person shows up to their doctor or primary care or in the emergency room—you know, these first-line physicians who see them who may not necessarily be thinking about it because they're not aware of them.

[00:23:52] Is there some prompt that the computer could say, "Hey, your person is coming in with these symptoms, consider this rare neuroimmune disorder?" And it wouldn't be a diagnostic tool per se, because I don't think we're there yet. But it'd be something to prompt the doctor or the clinician who's seeing that person at that time, being like, "Hey, think about this." So that's some of the other things I would hope that we can start creating in the future.

[00:24:17] **Krissy Dilger:** Wow, that is an amazing perspective. And I am curious to see what the world of diagnostic testing and treatments, and everything will look like in five or ten years once technology catches up.

[00:24:36] And we're so grateful—I want to speak on behalf of the rare neuroimmune community—to have clinicians such as yourselves and researchers who are doing this work and making a hopeful future for those who are diagnosed. So, thank you both, and thank you for joining me today on this podcast and sharing about yourselves as well as the clinic at Emory University and Children's Healthcare of Atlanta.

[00:25:01] **Dr. Grace Gombolay:** Thanks again for talking to us about this. It's been really fun.

[00:25:05] **Dr. Varun Kannan:** Yeah, happy to help out.

[00:25:09] **Krissy Dilger:** Thank you to our “Community Meets Clinic” sponsors: Amgen; Alexion, AstraZeneca Rare Disease; UCB; and Genentech. Amgen is focused on the discovery, development, and commercialization

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