Assessing the Impact of Social Disparities of Health on Disability and Access to Care in NMOSD Patients

You can view this presentation at: youtu.be/vBhHV8ULrQY

[00:00:00] **Roberta Pesce:** We at SRNA have a very exciting announcement to make that is tied to our next talk. SRNA's Eclipse Fund for Research has awarded the first recipient to the progress grant for NMOSD, made possible by a research grant from Horizon Therapeutics. The purpose of the progress grant for NMOSD is to help the broader NMOSD community understand how to improve diagnosis, treatment, and quality of life of people with NMOSD.

[00:00:32] Research projects may focus on access to care, mental and psychological aspects of living with NMOSD, clinical differences, improving diagnosis and clinical care, therapeutics, or basic science projects. Dr. Sammita Satyanarayan from the Icahn School of Medicine at Mount Sinai is being awarded $25,000 for her research study entitled "Assessing the Impact of Social Disparities of Health and Disability and Access to Care in NMOSD Patients." We're incredibly exited to have her join us today and explain a little bit more about her work. Welcome, and thank you so much for being here today and over to you.

[00:01:12] **Dr. Sammita Satyanarayan:** Hi. Thank you so much, Roberta. Thank you all for having me today. It's just an incredible opportunity to be here and speak to everyone. Just as another introduction, as Roberta said, my name is Sammita Satyanarayan. I am a neuroimmunology fellow currently at Mount Sinai Hospital in New York. We are so honored that SRNA has chosen our project to support this year. I think, as physicians, we spend years studying medical textbooks and we spend a lot of time looking at picture on computers, but at the end of the day I think we all got into this because we really want to understand how to help the person in front of us. And, for me, that really requires us to have a holistic understanding of what shapes our patients beyond the disease itself, understanding how factors in people's lives outside of genetics or biology actually affects how the disease impacts them even before they ever come to us in the clinic.

[00:02:03] So that's why our project today is focused around understanding the social determinants of health and their impact on access to care and disability in NMOSD patients. First of all, what are social determinants of health? I think one of the most important things we've learned in medicine in the last couple of decades is that there are aspects of our lives from the physical environments we live in, our social identities, and our backgrounds, our behaviors, to our economic stability and opportunity that can actually impact health and disease. In the world of public health, these factors are called social determinants of health, and differences in these aspects can lead to differences in the disease process, which I'm going to be calling disparities today.

[00:02:44] What drives us to look at this question is that if we better understand some of these factors that could be associated with differences in either access to care or disability, we can actually try to start addressing them and advocate for our patients on multiple levels. I know we've all had some great talks in the conference already about what NMOSD is, and I know many of you personally have experienced that. But just to review it briefly, it is a group of diseases where we see an autoimmune process affecting the optic nerves, the brain, and the spinal cord. And it has the chance to cause repeated injury if not treated. In some cases, we do have antibodies in the blood that identify a more specific diagnosis with NMO or MOG, but not always.

[00:03:26] So why would this be important to even think about in NMOSD? I think firstly in the last couple of decades we have come such an incredible long way in recognizing NMOSD as a distinct group of diseases that's different from MS. And while we can always learn a lot from MS research, we can't always assume that what's true in MS is the same for patients with NMOSD. Unlike MS, which historically was more prevalent in white populations, though that's changing as well, NMOSD is actually more diverse in the kinds of people that is affects.

[00:03:59] There has been some research in NMOSD that's looked at one type of social determinant with regards to race and actually did find some differences, most notably, that African American patients we're more likely to have severe attacks at onset and longer hospital stays. Though the connection there between that, race, and motor strike was a little less clear, but race is one factor and motor weakness is one type of disability. So, there's a lot left to understand about all of the factors that could be impacting a person's health from the beginning, even before they might be diagnosed with the disease. In order to understand it, we have to figure out a few ways of measuring these factors.

[00:04:37] So I think coming back to a couple of categories I introduced earlier, when we think about the physical and environmental sort of context, we think about our day to day, the safety and security of our housing, our transportation. Of course, it's hard to capture all of these things and their true complexities, so we use proxies, and we look at things like zip codes, city or state. Our social and community factors are things that are important to our identity, like gender, race, ethnicity, immigration status. When we think about economic factors, we think about economic stability, but also access to education and the quality of education. So again, we're looking at proxies to some of these factors with things like employment, education, insurance status, and even income.

[00:05:20] And lastly, there are, of course, things that we do, our own behaviors, such as smoking, for example, that could impact our disease process directly or indirectly. And there's always clinical factors about your body, perhaps your age, your body mass index, or any other medical conditions that you might have that impacts how the disease is unique in you as compared to anyone else. So that's sort of an overview of how we try to measure some of those predictors or those social determinants of health, but how do we measure the impact then on access to care and disability in this disease? So, for access to care, we look at actually time. We can look at the time from when a person had their first symptom to when they were actually given the diagnosis or for how long it took for them to start in therapy for their condition.

[00:06:06] And then for disability, we can look at a multitude of things, but first and foremost, we want to think about the people who are actually living it and understand whether they feel they have trouble with walking, for example, or having trouble doing the things that they want to do on a day-to-day. We can also look at the clinician's assessment of a person's walking. We can look at some standardized and validated disability scores, like the EDSS or the Timed 25-foot Walk, which measures how quickly someone can walk. And I think it has been mentioned earlier in multiple thinks today and over the last couple of days, particularly with NMOSD, we do have to think about disability from all angles outside of just the strength aspect.

[00:06:45] So we definitely also want to look at vision here and visual acuity. So, you might as the question how would we even begin to study this question? And I know that we just had an amazing couple talks on thinking about how we structure research, and so when we thought about answering this question, we thought about it in two ways. One with looking at data or information that was collected prospectively, meaning that you have a group of people who volunteer as part of the study and then you're followed over time. The benefit of that is that it's really in-depth. It's very standardized and it has a really regular follow-up. The downsides are that maybe you have some questions that weren't asked originally and maybe we might miss folks who didn't get the chance to participate in that kind of a study.

[00:07:26] So the other way that we can look at this is what we call retrospective where we have a group of people, and we look backwards to understand what types of exposures they had. Data collected prospectively is an amazing resource, but it can be rare, and particularly so with rare diseases. So, I wanted to take a moment to just give a shout-out to all of the patients and the folks at Guthy-Jackson Foundation for participating in and organizing this incredible study called CIRCLES within the last decade. It was really an amazing international collaboration of medical centers, patients, and the Guthy-Jackson Foundation to bring together a large group of people with NMOSD in the hope that we can really learn a lot more from a larger group of people with it.

[00:08:08] CIRCLES was an incredibly comprehensive study and all those participants who were in the study gave so much information. Some of the variables you can see highlighted in blue here are information that we have from people in CIRCLES. It's not everything, but I'll get to that in a moment. And similarly, when we think about our end points we want to look at, we, again, have most of the information we want. We don't have necessarily all the pieces of information on every single person and those are highlighted here in orange. So that's sort of why we thought about doing the second part of the study, which was to try to get at some of those missing pieces of information.

[00:08:43] And this is where we can actually try to get a little bit better sense of those factors from a retrospective study. It doesn't have the same advantage of following the same group of people in depth over a long time, but it allows us a finer degree of detail in the questions we can ask. And of course, whenever we look back in aggregate within our patients at medical centers, this is always done in an anonymous fashion, and the goal is to try to understand any patterns here that could help us with all of our patient care in the future. To that end, we're available.

[00:09:13] We're going to try to be really comprehensive in looking at some of these questions across three different academic medical centers, at Mount Sinai, USC and Massachusetts General Hospital. And I wanted to just sort of, again, show you that we would try to be looking at all of those factors that we had identified, with the end goal being that this project is going to allow us to better understand some of the factors that really impact access to health care and disability from this disease within our community.

[00:09:43] So with that, I'd like to just say a quick thank you to my research mentors, Dr. Katz Sand at Mount Sinai. Dr Amezcua at USC, and Dr. Levy at MGH, the Guthy-Jackson Foundation, and of course the SRNA for giving us the chance to even do this project. So, thank you very much.

[00:10:00] **Roberta Pesce:** Thank you so much, Sammita, for this very comprehensive overview of what you will be working on for the upcoming time, and we really appreciate it. I don't think we received any questions, and I also believe that we have reached out next session at this time. But, again, thank you so much for being here today. We truly appreciate it.

[00:10:19] **Dr. Sammita Satyanarayan:** Thank you. It's an honor.