

Health Disparities and Rare Neuroimmune Disorders

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[00:00:00] **Krissy Dilger:** Hello and welcome to the SRNA "Ask the Expert" podcast series. This podcast is titled, "Health disparities and Rare Neuroimmune disorders." My name is Krissy Dilger, and I will be moderating this podcast. SRNA is a nonprofit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our website at wearesrna.org. Our 2022 "Ask the Expert" podcast series is sponsored in part by Horizon Therapeutics, Alexion, AstraZeneca, Rare Disease, and Genentech.

[00:00:37] Horizon 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. Horizon believes science and compassion must work together to transform lives.

[00:01:00] 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 is always at the forefront of their work.

[00:01:26] 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.

[00:01:52] For today's podcast we were pleased to be joined by Dr. Mitzi Joi Williams. A World-Renowned Multiple Sclerosis Expert, Dr. Mitzi Joi Williams is a Board-Certified Neurologist, Fellowship-Trained Multiple Sclerosis Specialist, Author, International Speaker, and Researcher who is passionate about educating and empowering people affected by MS. She is the proud recipient of the Multiple Sclerosis Society's Hope Award and the 2019 BlackDoctor.org Top Blacks in Health Care Award. She is also the Amazon Number 1 best-selling author of *MS Made Simple: The Essential Guide to Understanding Your Multiple Sclerosis Diagnosis*. Her research on Advancing Care and Outcomes for African American Patients with Multiple Sclerosis was published in April 2022 in the Green Journal.

[00:02:46] Dr. Mitzi received her undergraduate degree from Emory University in Atlanta, GA, and received her Doctor of Medicine Degree from Morehouse School of Medicine in Atlanta, Georgia. She completed her Internal Medicine Internship, Neurology Residency, and Multiple Sclerosis Fellowship at Georgia Health Sciences University (formerly MCG) in Augusta, GA, where she received numerous awards and scholarships and served as Chief Resident of the Neurology Residency Program.

[00:03:17] She has worked in a variety of clinical settings including academic teaching hospitals, private practice, and as Medical Director of a Multiple Sclerosis Center. She is dedicated to raising awareness about the importance of research participation and encouraging diversity in clinical research. She is the proud Founder and CEO of Joi Life Wellness Group Multiple Sclerosis Center™, where she provides personalized Multiple Sclerosis Care delivered with expertise, compassion, and joy. In her spare time, she enjoys spending time with her husband and two beautiful children and singing.

[00:03:54] Welcome and thank you for joining me today. Can you begin by just defining health and health disparities?

[00:04:01] **Dr. Mitzi Joi Williams:** Absolutely. Health disparities or health encompasses many things, right? Typically, when we think of health, we think of something physical, right? And so that is a component of health, our physical body, how we feel, our ability to move around and do the things that we want to do, our energy level, those types of things. But there's also emotional health. And so, all of those things are tied together. So, if we think about wellness, it encompasses both the physical aspect as well as the emotional aspect of our health.

[00:04:36] When we think about health disparities, health disparities really represent differences in outcome that are not actually based on differences in health care needs. So, if two people have hypertension and they both need the same type of medicine, but one person doesn't have access to it and therefore has poor outcomes like a heart attack or stroke, that is a health disparity, right? So, they have the same needs. But someone is not able to access health care for some variety of reasons and so they have poor outcomes not because they have more severe disease, but because they don't have access to get the care they need.

[00:05:12] **Krissy Dilger:** Great thank you for that explanation. So, what is the difference between individual health and population health?

[00:05:21] **Dr. Mitzi Joi Williams:** So individual health is based on many different things, including oftentimes that person's genetic makeup. There are some diseases and conditions that are inherited. Population health is more how an overall group is doing, for instance, that could be broken down by women's health or men's health. Or it can be broken down in terms of race or ethnicity or location, rural versus urban populations. So, group or population health can be broken down into many different categories, whereas on an individual level there are things that we take into account such as a person's genetic makeup and other social determinants of health as well.

[00:06:05] **Krissy Dilger:** Okay, thank you. Our next question is, what does this term 'social determinants of health' mean? And how do they impact health? Why are they important?

[00:06:16] **Dr. Mitzi Joi Williams:** So, social determinants of health are important, because a person's overall health relates to many factors. So, it's not just your ability to go to the doctor and get medications. There are many things that can factor into your ability to access the system, so to speak. Social determinants of health include things like where you live, your ability to have transportation to take you to different appointments, etc. Social determinants of health also include things like your socioeconomic status, your access to insurance, and many other things, your access to healthy foods, where you live. There are some people that live in what we call "food deserts", where they don't have grocery stores. And they may have to obtain most of their groceries from a convenience store. And that certainly can affect the things that you take in which affect things like your blood pressure, your cholesterol, etc., etc. So, social determinants of health are all of those things outside of, let's say, your genetic makeup that affect your ability to access care. And also, things like discrimination and racism can also be a part of social determinants of health.

[00:07:24] **Krissy Dilger:** Thanks. Yeah, that's a lot to take in, but that's really important. How does access to resources impact health? And how do economic, social, and environmental factors impact health? And who is most impacted by health disparities?

[00:07:43] **Dr. Mitzi Joi Williams:** So, marginalized populations are traditionally most impacted by health disparities. Many of them we consider ethnic minorities here in the United States, although they may be majorities in other parts of the world. But certainly, ethnic minorities, people of lower socioeconomic status who don't have as much money as others, certainly their access to care can be impacted by the type of insurance they have as well as things like the type of job they have. If someone has an hourly job it may be more difficult for them to take off work to do maintenance health care and preventive visits versus someone who may be a salaried worker and has time to take off for procedures and other types of things.

[00:08:26] So that socioeconomic access definitely affects a person's access to care. Environment can also affect an access to care, as well as health outcomes in terms of if someone lives in an environment with polluted water. If you live in an environment where you don't have, again, access to groceries, healthy foods, healthy choices. If you don't have access to a safe place to walk and exercise. All of those things impact the eventual outcomes that we see. So again, all of that plays into those social determinants of health.

[00:09:05] **Krissy Dilger:** Great, thank you. So, we've addressed some of the ways in which these social determinants of health impact people. How can we address or mitigate the impact of some of these health disparities?

[00:09:20] **Dr. Mitzi Joi Williams:** Yeah, so I think the first thing to recognize, and this is what I tell all of my patients, is that you are your own best advocate, right? So, you or those that you love, if you love someone or care for someone who has a health condition, trying to find out about whatever resources are available is hugely important. So, for instance, I work with a condition, multiple sclerosis, which is a disease that is not very common in the United States. And I also work with patients who live with neuromyelitis optica, which is even more rare than MS. And so, you have to be proactive about finding out about what resources are available to you.

[00:10:03] For instance, in our field, they're often free resources where people can get their medications for free. They may be able to get their MRIs or testing for free. But if you don't know about those resources then you can't access them. Joining parts of a patient community, joining foundations, other resources within that field. Also listening to podcasts like this one, where we may be talking about these issues. Educating yourself is hugely important. So, on the patient's side, educating yourself about the options that are available. Educating yourself about resources and asking questions is extremely important, because your health care team is supposed to be there to help you. So, making sure that you ask questions and are engaged.

[00:10:45] From the side of a person who works in health care such as myself, ways that we can help decrease disparities are: 1. To raise awareness about the fact that they exist, 2. To try to make our patients aware of resources that are available, and 3. To try to come up with strategies to try to address some of the issues that we see. And they'll be different in different communities. The issues that I may have with access for a patient in rural Georgia may be very different from someone who lives in Michigan. So, looking kind of locally to see what is available and making sure that my patients know about that is important. And also, as a health care provider partnering with the community to make sure I understand the needs and are not just assuming what's needed is extremely important as well.

[00:11:30] **Krissy Dilger:** That's a really great point. Yeah, I think even understanding the problem is half the battle. Yeah. So, you kind of just answered what my next question would be, which is how can health care

providers help bridge the gap. So, we are an organization that advocates for people with rare neuroimmune disorders related to multiple sclerosis. Are there any specific ways in which the rare neuroimmune community is impacted by health disparities?

[00:12:04] **Dr. Mitzi Joi Williams:** Absolutely! So, the rare autoimmune community can be impacted by disparities, because there may be many providers that are not aware of, let's say, current trends and treatment, current treatment options. I am a specialist within neurology, which is a specialty. And so, depending on if you have access to a specialty care center, you may or may not have someone that has expertise that may be up on the latest research that may know about the latest resources. And so that can be a difficulty depending on where you access your care. Also, there may be availability issues. So, some of my colleagues that work in different types of practices may have a waiting list that's out six or seven months for a follow up. So, all of those things play into disparities, your ability to be able to access the system, see your doctor, ask questions, and your access to expertise can certainly affect your outcomes as well.

[00:13:06] **Krissy Dilger:** Great, thank you. So finally, according to your research, because I know you've done research on these issues, how do environmental and geographic factors affect access to health care? And are there certain things that affect people? For instance, with neuromyelitis optica or transverse myelitis or one of these rare disorders specifically.

[00:13:35] **Dr. Mitzi Joi Williams:** So, I think diagnosis is extremely important and sometimes can be affected by your geographic location. Again, there are some hospitals and hospital systems where they don't have access to a general neurologist, let alone someone with specialty care. So, your ability to be diagnosed may be delayed in some cases which can certainly impact outcomes with neuromyelitis optica, the episodes of relapses can be devastating. And someone can be blind from one episode. So, if we don't diagnose it early people could have very severe disability that potentially could have been prevented. So, it can affect diagnosis also affect treatment for acute episodes. Again, if someone doesn't recognize or know very much about that disease, they may not recognize an episode and be able to treat it appropriately.

[00:14:30] And then if you think about environmental factors, again, there's a lot that we don't know about rare autoimmune diseases. We're learning a lot about environmental factors. Are viruses associated? Are there other factors that may be triggering these diseases? So, certainly it is plausible or possible that people who live in certain areas may be more affected than others. But I think there's still a lot that we have to learn about environmental factors and how they play a role.

[00:14:58] **Krissy Dilger:** Yes, definitely. So that's the rest of the questions that I have. Was there anything you wanted to add or mention before we wrap up?

[00:15:08] **Dr. Mitzi Joi Williams:** I think that if I had to add anything, I would say that knowing is half the battle, right? And I think it's very important that we have these conversations to really address the fact that disparities do exist, right? Because we can't address things that we don't know exist or that we don't see or recognize on a regular basis. And then I think the next piece that's extremely important is for us as health care providers to partner with our patients and their care partners to really understand what the needs are in our community and try to come up with solutions to address them. We know that we won't fix all health care disparities in the day. We won't fix it in a week or a month. But if we first begin to listen to each other and try to understand, I think that's the first step in really moving forward and increasing health equity.

[00:16:01] **Krissy Dilger:** Great, thank you so much. And I guess just as an add on for that, is there anything that we as, we're a nonprofit community-based advocacy organization, is there anything you would say that we can be doing to actively help bridge these gaps?

[00:16:19] **Dr. Mitzi Joi Williams:** Well, I think again, the first thing is listening, right? Listening to those who are a part of your community, right? So, are there ways to have, let's say, a focus group, right? Or a listening party of some to talk about these issues. So just like you talk about them with me, the people living with these conditions may have other topics that may be of importance.

[00:16:40] I've done some work with health disparities with different organizations and it's very interesting that we did a project with what we call tethered surveys where we ask the patients a question and we ask the doctor. So, we ask the patient, "What's important to you?" And we ask the doctors, "What do you think is important to the patients?" And sometimes the answers matched up and sometimes they didn't, right? So first we have to be talking the same language and making sure that we're all looking at what the priorities are. And then again, partnering with our community partners, our patient advocates, and others to see how we can come up with plausible solutions. Even if it's something like an information package, right? Or a list of resources for that condition. Who provides what within those resources? I think that those are always to kind of get the ball rolling and then work towards bigger issues like policy and health care disparities, research, things like that.

[00:17:41] **Krissy Dilger:** Great. Thank you so much. Yeah.

[00:17:43] **Dr. Mitzi Joi Williams:** You're welcome!

[00:17:43] **Krissy Dilger:** I really appreciated you taking the time to meet with us.