

# Social Determinants of Health in 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, "Social Determinants of Health in Rare Neuroimmune Disorders." My name is Krissy Dilger and I moderated this podcast. 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](https://wearesrna.org). Our 2023 "Ask the Expert" podcast series is sponsored in part by Horizon Therapeutics, Alexion, AstraZeneca Rare Disease, and UCB.

[00:00:36] 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.

[00:01:01] Alexion, AstraZeneca Rare Disease is a global biopharmaceutical company focused on serving patients with severe and rare disorders through 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. UCB innovates and delivers solutions that make real improvements for people living with severe diseases. They partner with and listen to patients caregivers and stakeholders across the health care system to identify promising innovations that create valuable health solutions.

[00:01:44] For today's podcast, we were pleased to be joined by Dr. Elizabeth Wilson. Elizabeth Wilson is a pediatric neurologist at Cincinnati Children's Hospital with specialized training in neurology and neuroimmunology. She received a Bachelor's of Science in Neuroscience from Lafayette College in Pennsylvania. She then completed medical school at Boston University, pediatric residency at Boston Children's Hospital / Boston Medical Center and pediatric neurology residency at Boston Medical Center. She went on to pursue a fellowship in neuroimmunology at Massachusetts General Hospital slash Boston Children's Hospital. She recently became the Director of the Multiple Sclerosis and Neuroimmunology Center at Cincinnati Children's Hospital.

[00:02:35] Through her research, she aims to understand how a patient's environment, including life stressors, interacts with their body and genetics and inflammatory neurologic conditions such as multiple sclerosis. She believes that by studying this relationship, we can better manage these disorders and advocate for changes that will improve patient outcomes. Welcome and thank you for joining me today. To start us off, do you mind just telling us what does the term social determinants of health mean?

[00:03:08] **Dr. Elizabeth Wilson:** The social determinants of health have been formally defined by the World Health Organization, but they are really any non-medical factor that can influence a patient's health outcome. It's the conditions in which a person is born where they grow up, where they work, where they live. These factors are thought to influence and create unfair differences in health outcomes. You can see those differences

from local health disparities to international health disparities related to countries health care. We know from studies that have looked at these factors that health tends to follow a social gradient and that patients who have social hardships or lower socio-economic status do tend to have worse health outcomes overall.

[00:04:11] **Krissy Dilger:** Thank you for explaining that. This is such an important topic in health care but also for our community. How does access to resources impact health? For instance, how do economic, social, and environmental factors impact health and health outcomes?

[00:04:32] **Dr. Elizabeth Wilson:** I think this was something that I found really surprising as I was delving into this topic early on in my medical career. And there's this really great graph of how various factors impact our health outcomes. And I think that we as medical providers love to think that the medical system and medications improve patient health, which it does. But when you look at how much just medications impact health outcomes, it's very small, it's somewhere around 10%. And when you look at a person's genetics, it might be about 30% in terms of a contributor to their health outcomes. And then when you look at social factors, it's 15% of a patient's health outcomes. It's somewhere between direct medical care and a person's genetics.

[00:05:27] So, certainly something that can impact health at a large level and some examples of that have been around access to housing and access to food. We've had studies looking at housing insecurity in pediatric patients, for example, and we've seen that housing insecurity is associated with decreased overall health in children, but also associated with an increased risk of developmental concerns in these kids. When we look at food and access to food, food insecurity has been associated with an increased risk of hospitalizations and an increased risk of healthcare utilization overall. So, things like emergency department visits.

[00:06:17] Something that's important to note when we think about how social factors may relate to health outcomes is the role that race plays in social hardships. A lot of studies will look at race almost as an independent factor in predicting health outcomes. It's really important to emphasize and understand that race is largely a social construct. It's something that our society has created and that a lot of the differences we see in health outcomes that may be related to race or seen in different racial groups could be and I think are likely not directly related to race but more directly related to that chronic stress that these patients are experiencing as being part of a marginalized group, and potentially as having more social hardships related to that chronic stress.

[00:07:23] **Krissy Dilger:** That makes sense. That's really interesting to think about and probably not something most people can connect just when they're just thinking about these things from their everyday life. But when you really dive into it - yeah, it's important to know these things. Who is most impacted by health disparities? Is there specific group of people or what does the research tell us about that?

[00:07:51] **Dr. Elizabeth Wilson:** I think the takeaway is that the experience of social hardships is pretty prevalent and that almost anyone can experience a hardship. I would say anywhere from 50-60% of kids coming from just a pediatric background. But about 50- 60% of kids will experience some hardship throughout their life. It's a large chunk, but I would say that patients who might be at higher risk of having hardships would be anyone that's coming from a marginalized group. So, people who are a minority, people who maybe are immigrants have difficulty accessing health care patients who aren't speaking English as their first language. And then even just location like patients who are living maybe in more rural regions might be more likely to have other hardships related to just access to care, access to good food resources, and other social services.

[00:09:00] **Krissy Dilger:** Thank you. What are some ways in which medical providers may contribute to health disparities? As a follow-up, is there a way that they can bridge the gap for those who are negatively affected by health disparities?

[00:09:21] **Dr. Elizabeth Wilson:** I think there's a lot of different ways that medical providers contribute or propagate some of these health disparities related to social hardships. One of them, I think that just right off the bat comes to mind in the neuroimmune world is implicit bias related to the medical training that we receive. There's been a lot of publicity about how medical training leads providers to have these illness scripts in their head of the classic patient to present with certain disorders.

[00:10:00] For example, MS was always thought to be a disorder of white women, but it certainly can happen in other racial groups. And we've certainly heard examples of black women being told they couldn't have MS because of their race. And I think this is hopefully changing now. But it's certainly, I think a way in which the medical system as a whole propagates some of these disparities and in diagnosis and care.

[00:10:37] The other way in which the medical field contributes to these disparities is just through the structure of research and how we're studying disorders. A lot of the standardized studies that have been done have largely been conducted in white patients and they aren't necessarily trying to recruit patients from minority groups or patients from various socio-economic backgrounds. I think those patients are often underrepresented in these studies, which makes the results harder to generalize. I think part of it is just gaining some more experience with these patients in their research trials.

[00:11:27] And then just two other examples of how health care propagates some of these disparities. One is in just access to subspecialty care. A lot of the subspecialists are located in large cities at large academic centers. Patients who are in more rural areas will likely not have access to a subspecialty clinic. And we know that in multiple sclerosis and neuroimmunology clinics, there are fewer minorities that are represented in that patient population. So, they're oftentimes not even making it to a subspecialist.

[00:12:08] The last example is the way that the health care system historically has contributed to isolation and mistrust of minority groups or patients that are experiencing hardships and are considered to be a vulnerable population. We often hear examples right from race studies and the Tuskegee Syphilis trial, which certainly propagates mistrust within the black community with the health care system. Even more recently, there have been examples of prisoners who have been treated with Ivermectin, not knowing about it, or immigrants who have had gynaecologic procedures that weren't really aware or appropriately consented for those procedures.

[00:13:06] I think it's important to acknowledge that these patients that are coming from vulnerable positions where there's a large difference in the power dynamic when they come to a physician's office are having a very different experience than maybe some patients who feel more empowered to interact with the health care system on a more equal playing field. I think those are some ways in which we definitely help propagate these disparities.

[00:13:36] And then what do we do about it? I think the first step is just acknowledging that these differences do exist and that not everybody is going through the health care system with the same experience and that different patients might have different social backgrounds that are impacting their health that we maybe aren't even asking about. I think we can include more patients from diverse backgrounds and research studies. And by diverse backgrounds, I don't only mean race but making a really conscious effort to include patients who are coming from different geographic areas, different socio-economic backgrounds in the clinical trials, I think will help make them much more applicable to our patients overall and to providers on the larger scale.

[00:14:36] And then on the day-to-day, what providers can do is just try to ask about some of these social factors that we maybe don't think about because we're so focused on their medications and the blood pressures and the routine things that we're getting in clinic and it can be something as simple as having a survey that's built into your intake when you come to clinic, just asking about some of these hardships and

connecting patients with resources, partnering with social worker, and to make sure that we're addressing the patient as a whole, including the environment that they're coming from and any needs that they might have, that's not directly related to their medication management.

[00:15:21] And then I think it's also important for us to help connect patients with other people that are living their shared experience. Reaching out to some of the more national groups like the MS Society or SRNA and helping to form support groups around race, around language, or age so that patients feel like they have a community, even if they have a rare disorder.

[00:15:56] **Krissy Dilger:** That's great. Very, very good ideas there. And I appreciate you for sharing all of those. So, we talked a little bit about this already, but I guess I wanted to ask to see if there's any more you wanted to add. How do social determinants of health impact the rare neuroimmune community specifically?

[00:16:21] **Dr. Elizabeth Wilson:** Yeah. I think this is a really interesting question that we're just recently starting to gain more knowledge about. There have certainly been studies in patients with multiple sclerosis who are adults and have shown in several different ways that patients with MS who have social hardships have worse outcomes, meaning they have more active disease, they have increased interactions with the health care system.

[00:16:56] And more recently, what I tried to do during fellowship is look at how these social hardships are affecting early disease course and early neuroinflammation. We looked at pediatric patients and we saw that children with MS were developing symptoms and being diagnosed at a younger age compared to patients who did not have any hardships. I think that's really an interesting and important point to acknowledge that the disease itself might be acting slightly differently just based on the patient's environment and exposure to chronic stress. And there are ongoing studies on NMO and MOG.

[00:17:44] So, our other two MS cousins, if you will, and they have found at least in the early data analysis, similar results, they have not been published yet, but just in hearing about them at conferences, I think there's going to be a lot more coming down the pipeline related to those disorders as well and not just in age and socio-demographic or socio-economic factors. There also have been studies looking at race, which we talked about is a marker of just overall chronic stress in some ways. And there have also been studies in patients who have MS and who are black and have found that they have poor outcomes related to their MS as well and more severe disease courses. So, certainly some very interesting research that's been done that has shown that there is a very real impact of this environmental chronic stress that is interfacing with neuroinflammation and disease course over time.

[00:19:00] **Krissy Dilger:** Well, thank you. And I'm looking forward to seeing what is coming down the pipeline that you mentioned. And I guess rolling off that answer into my next question, we already touched on this. But, is there research into the social determinants of health and neuroimmune disorders? And also in your opinion, what research needs to be conducted into this topic?

[00:19:31] **Dr. Elizabeth Wilson:** There is definitely some research done, especially in the adult world, I think primarily in multiple sclerosis. But there is I think a movement now to expand that research into other neuroinflammatory conditions and into pediatric populations to study different disease time points. But I think some of the work that's been done has been trying to understand what it is about the experience of these social factors or social hardships that is causing the difference in how the disease is developing over time.

[00:20:17] Some early research has been done in looking at just overall chronic stress and the experience of discrimination and biomarkers of inflammation. And those early studies have shown at least some relationship

between chronic stress and gene expression that regulates inflammation. I think that's a really interesting possible explanation to how social factors are interfacing with these disorders that needs to be studied a little bit more but is very intriguing.

[00:20:01] And then more recently I mentioned work around the pediatric multiple sclerosis population. And really that work has been to just describe what the prevalence of social hardships are in pediatric patients with MS. And we found that about 66% of kids with MS do experience hardships. So, certainly something that we're going to need to address and raise awareness about. I think the first step is just describing the problem. I think that's where we are currently with that.

[00:21:40] And then I touched on this, but I think the next steps really will be trying to expand the diversity of the patients we're studying in standardized research protocols. And then once we describe the problem and understand how environment is interacting with neuroinflammation, I think the next logical question is what do we do about it? And where do we go from here? And I think that's an equally exciting question because there could be protective factors that we could help our patients connect with to limit the impact of chronic stress on their disease course. Because we might not be able to change the system right now, and I would love to. But while we're waiting for that to happen, are there things we can tell our patients to do on a day-to-day level that could help protect them from that experience of social hardships and chronic stress?

[00:22:52] **Krissy Dilger:** That's great. All very interesting and raises so many questions too, like you said, it's just where we're starting, but definitely not where we're ending. I appreciate you walking me through that. That's mostly all the questions I have for you. I did want to open it up to see if you had any more. Anything else you wanted to comment on or leave us with before we wrap up?

[00:23:16] **Dr. Elizabeth Wilson:** No, I think that I'm so glad that you all invited me to participate in this podcast. I think I love talking about this topic and raising awareness about it. I think if I had to leave just some take-home messages for the providers, I would say work with your team, establish a relationship with a social worker, and ask about these questions, these social hardships that our patients might be experiencing and try to connect them with resources to address them. And if you don't have the ability to do that in clinic, try to connect them with some of these national organizations like the SRNA that have amazing resources and support for patients. We can help provide some hope for them and help build some resiliency and for patients that are experiencing these hardships.

[00:24:16] And then anyone who's looking for additional training or hoping to be an immunologist, we need more. And I think that if we are able to get more of us throughout the country, in more rural regions, then we can help to at least address some of the hardships that are coming from just inability to access those specialty care. And if patients are listening to this talk to your doctor about these issues, feel free to bring them up on your own. It's hard sometimes I think when the physicians don't provide an outlet to talk about social stress, but it's important. And we're here to help and address all aspects of the patient's health, and that includes these chronic stress factors.

[00:25:12] **Krissy Dilger:** Thank you so much. Those were such great important points to make and I hope this is just the beginning of the conversation. I really enjoyed talking to you today and learning from you. I'm sure our community will as well. And I hope to talk to you again in the future and hopefully we'll be further along in the research.

[00:25:35] **Dr. Elizabeth Wilson:** Yeah. Thank you so much.