



PODCAST

Diversity in MS Research and Clinical Trials

Episode 168 – Podcast Transcript

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Stephanie Buxhoeveden: Welcome to the Can Do MS podcast. I'm your host Stephanie Buxhoeveden. I live with MS, and I'm also a clinician and MS Researcher. This is episode number 168.

Today, we're excited to welcome our guest, Dr. Jacqueline Rosenthal, who's a neurologist at Shepherd Center in Atlanta. She's also served in the US Army and works tirelessly to increase awareness and address the needs of under-represented MS patients. Welcome, Jackie.

Dr. Jacqueline Rosenthal: Thank you. I'm excited to be here and discuss multiple sclerosis with you today.

Stephanie: Awesome. So, let's talk about the not so distant past when MS was thought to be predominantly a disease of Caucasians who were of European descent, but now we know that that's far from the truth. Correct?

Dr. Rosenthal: Correct. Absolutely. Yeah, we know now that MS can affect most anybody. Unfortunately, we don't have specifics on every single racial and ethnic group, but what we have learned are that Black women, in particular, are the fastest growing group of individuals diagnosed with multiple sclerosis, um, and that Black and White people is pretty similar in terms of the proportion of people that are- that are... that have MS. Um, other groups, again, you know, Hispanic population, if you were to look at a chart that shows the different prevalence and that sort of thing, going to be a little bit lower, and then, um, our Asian population, a bit lower than that, but again, we're really missing a lot of specifics even within Asian ethnicities, there are so many different types and that sort of thing. Um, Native American, we hadn't have no information about that, you know, so we have to ask ourselves, is the incidence really that low or are we missing cases? [(2:00)] And so, really need more information. But yeah, that's the kind of outdated opinion that, um, MS is like a White woman's disease.

Stephanie: Definitely. It can hit anyone at any time. It's important to know that. So, what impact does race have on MS.

Dr. Rosenthal: It's hard to know because, you know, when we look at race, it's so closely tied in to, you know, social aspects. We see, just looking at, you know, the big picture of, for example, that Black individuals with MS and Hispanic individuals, as well aren't doing as well. When we look at our Black MS community, in particular, they tend to have a more rapid course, more severe

relapses, um, you know, not recovering as well in between relapses, um, potentially not even responding to treatments as well compared to the White MS community, and so when we look at that, trying to tease out, "Okay. How much of that is the differences in the disease process itself?" or a biolo- biologic, genetic, and then how much of that is potentially due to, um, disparities and health care and access to care, social inequities, that sort of thing.

Stephanie: Absolutely, because as we know, delayed diagnosis really impacts long-term prognosis, so the earlier you're catching it, the better people do.

Dr. Rosenthal: That's what we always say, time is brain, you know. We want... we know that the earlier we are starting those treatments, the better the outcome is.

Stephanie: Absolutely. Now, you mentioned communities who don't have ready access to specialists. What options are there for those who don't have access to an MS specialist right down the road?

Dr. Rosenthal: It's really hard because a lot of the MS specialists and the big comprehensive MS centers are in very urban or academic areas are ti- are closely tied into academic centers. Um, so that leaves a whole lot of the geography that are left without, um, easy access. And then you tie into that, as well, potentially, you know, a lack of resources, [(4:00)] you know, having the finances, transportation, time off work in order to be able to travel, so it can be really- really hard, um, when you're, um, not close and then don't even have the resources or time to try to get into an MS center. But it is so encouraged 'cause we know that you seeing that MS specialist can potentially, um, lead to better outcomes, so we try to train and help our community neurologists and people in rural areas on how to better diagnose and treat multiple sclerosis, so that's a kind of an ongoing outreach there.

Um, I have people who maybe I, kind of, co-manage with local neurologists, and so they don't necessarily have to come see me as frequently, um, and that can work out, as well, too.

Um, since the pandemic, fortunately, we have used- started using Telehealth a lot more, which is something that's been a huge advantage outside of even, you know, the pandemic. It's- it's makes it really a lot easier for people who are otherwise may be well-controlled, um, to continue to see their MS specialist, check-in, take care of things without having to necessarily travel in. That does not work as well for people who maybe aren't diagnosed and need to be diagnosed to try and do all of that, uh, via Telehealth or virtually, but it's made being able to continue care with an MS center a lot easier for a whole lot of people.

Stephanie: Yeah, absolutely. I think it's nice when MS specialists can coordinate care with somebody who's local, and same thing goes with all of the rehab specialists, Telehealth options for mental care, for rehabilitation, and sometimes, it's hard to know where to start, so I like to point people at the MS Navigators. We'll throw a link to that program in the chat. But the [inaudible] MS society is a good idea of who exists around the country and just calling them to ask the question of what your options are can be a really good place to start because it is overwhelming.

Dr. Rosenthal: It is, and there are a lot of resources out there that are underutilized by [(6:00)] the communities that probably need them the most. This is just for... just not knowing about them, and so and MS Navigators is a perfect example of, um, where you can get a lot of good information

and assistance.

Stephanie: Awesome. So, lack of diversity has historically been a real challenge in MS research. You mentioned there's so much we don't know about different subpopulations of MS patients. Have you seen any consequences in your own underrepresented populations?

Dr. Rosenthal: You know, I think that for somebody, when they're diagnosed with MS, it's very scary, and, you know, then we talk about these disease-modifying treatments. Um, they are terrifying sometimes if you just read about them, especially if you're somebody who's maybe never had to deal with anything medically before. Um, and so, then, to be in a minority group and you're, kind of, hearing about these studies and you realize that you're not represented in those studies, it does cause concern for certain... for some people. And so, I think that it's important to have adequate representation or research so that when we have our patients in underrepresented communities that, you know, when they ask what that... we could say, "Yeah", you know, "People like you, that look like you, with your same racial ethnic background, this drug performed the same- the same way," um, because that is a cause, uh, for concern for- for some people, you know? And when we talk about differences in response to treatment, it makes it so that sometimes, it's really hard to, kind of, you know, answer those questions.

Stephanie: Yeah, absolutely. F- for drug trials, are enrolling 90% Caucasian participants who are between the ages of 18 and 55 or 60...

Dr. Rosenthal: Hm.

Stephanie: ... Then, it's no wonder why post-marketing or after the drug is released into the general population who is much more diverse, has a much more, uh, wide range of comorbidities, of access to care, of living situations, this is why we see in the real world, things don't always look like they do in clinical trials.

Dr. Rosenthal: Absolutely. Yeah. And- and it- and [(8:00)] when we, you know, we want to be able to try to get it right the first time in our Phase III, in, you know, I through III clinical trials rather than having to do aftermarket trial, Phase IV trials, it- to try to get that additional information, we'd like to have it really, you know, at the beginning for our patients.

Stephanie: Yes, and I think that's where the expertise of the MS specialist really come into play and another reason why it's so important to have access to one.

Dr. Rosenthal: Absolutely.

Stephanie: So, what is being done to fill these gaps in our knowledge, and where can people learn more about ongoing work?

Dr. Rosenthal: So, there definitely are efforts to enhance diversity in our clinical trials. And so, you know, there are trials that will be done after the drug is already approved, that are specifically looking at to enroll minority communities to see how the drug, um, is behaving in those communities, to make sure that it is as effective as it is, and, you know, the larger populations from the Phase III trials, so that's certainly helpful, but outside from that, like I said, trying to get the participation at the very beginning would be great. So, just trying to spread the word about clinical

trials, I think it's very, um, misunderstood in a lot of communities, as well in terms of what it entails and what are the safeguards, the protections that are going to be, um, in place to, um, keep you safe as you're in these clinical trials, um, and then just knowing, you know, if you are interested how to go about even participating, the different types of studies there are because not everything is necessarily going to be a medication or a drug. You can still contribute to research a lot through other avenues, you know, looking at symptomatic management, bladder pain, sleep, um, different physical therapy, therapy trials, diet, there's so many different ways to contribute to research, um, and some are going to be a lot less invasive, um, in a way to, kind of, still, um, help out your community.

You know, registries is another one. It's like the easiest kind of study to- to participate in, um, and there are- [(10:00)] there's a registry now that's just specifically for African-Americans with multiple sclerosis, again, trying to, kind of, highlight what are those- what are the needs of the community and anything, um, special that needs to still be addressed. So, that's another easy way to- to try to address the- the- the gap in knowledge that we have right now.

Stephanie: Yes. And I'm so glad you called that registry out. Again, will link to it in the description of the podcast, but that's the National African Americans with MS registry, right?

Dr. Rosenthal: Yeah, that's it.

Stephanie: Yeah. And I would like to echo the point that you made where you can absolutely make great contributions to research without ever enrolling in a drug trial if you're uncomfortable with that. Um, I, myself, try to participate. I'm lucky, I live right near the National Institutes of Health, so I've enrolled in a lot of their clinical trials, but when I've lived in other areas, I've taken advantage of trials going on. So, I've done, I think it was a four to six-week just exercise program, and they measured my cognition and fatigue, and they split two different groups comparing more cardio and more weight lifting, and it was a neat experience because I learned about myself and my body through that experience. So- so, it's not all one-sided that it does have a mutual benefit. Um, and then, I have also been in the position of losing my insurance between having jobs...

Dr. Rosenthal: Mm-hmm.

Stephanie: ... And actually enrolled in an MRI study where I got free MRIs to be part of this clinical trial, and again, mutually beneficial because I didn't have insurance to pay for those MRIs and I'm contributing to research. I stayed enrolled in that trial, and I've been, um, going there every year for about eight years now, learning about my disease, learning about my, uh, lesions, having access to these cutting-edge tests that only people enrolled in these research-type settings get access to, so don't knock it till you tried it. It's kind of cool.

Dr. Rosenthal: It is, you know, and- and it's kind of, you know, some may argue it's a pro, others, a con, but you do get a lot of extra attention in a lot of these research [(12:00)] studies, um, and so on one hand, you know, someone may say, "I don't have time for this. It's too many visits," but on the other hand, I mean, you are- you're seeing someone really frequently and you're learning a lot and getting a lot of, um, information, um, so a lot of, again, ex- extra appointments but extra-extra attention and easy access to- to your medical team.

Stephanie: Yeah, and contributing data is so important. I, myself, am using registry data and bio

samples that have been banked, uh, for my own research. So, even if you don't have time to get out and do a trial that involves visits, getting online and filling out some surveys can actually be incredibly meaningful.

Dr. Rosenthal: Absolutely. And I'll even just add to that, um, to anybody, if you, you know, um, are thinking of pregnancy or get pregnant, and you're having to take a medication to definitely do the pregnancy registry. Unfortunately, nobody really does studies on pregnant women, and so all of our information that we have to allow, um, women with MS to, you know, safely conceive and- and- and start their families, a lot of that does rely on the registry data that we have from women, uh, who, uh, enroll in those studies.

Stephanie: Absolutely. And you have worked with Can Do MS on a really cool program. Can you tell us a little bit about the Black community meet-ups and the opportunities within Can Do MS?

Dr. Rosenthal: Yeah, so that's been a lot of fun. Um, and there are four different meet-ups over the year, and we just kind of address different topics that... and we get it from, you know, stakeholders and from the community and things that they want to talk about, um, and they're... I like them because they're a little different in that it's not just being lectured to for an hour. Um, there's a little bit of the education piece, but a lot of it is discussion, um, hearing from the community, um, them asking questions, them talking to each other and providing support, so it's been a great experience.

Stephanie: Awesome. Hopefully, we'll see some of our listeners at those meet-ups.

Dr. Rosenthal: [chuckles]

Stephanie: Now, if we've convinced anyone listening today to look into participating in [(14:00)] research, where can they go to find out more information?

Dr. Rosenthal: I would say to first check with your neurologist because they are going to have the best idea of what research you may be a good candidate for, um, just to get... have little guidance there. Um, outside of that, clinicaltrials.gov, um, has all of the different clinical trials listed. Um, it can be a little overwhelming when you go out into that website, but fortunately, you can filter it out by region and what kind of studies, you- you know, you're looking at, what, kind of... your age, MS type, and it can, um, narrow it down that way.

Um, there's also, you know, National MS Society and other, um, databases that can send out information about different kinds of research that's on-going.

Stephanie: Yeah, I get those emails a lot about opportunities to participate, to take a survey...

Dr. Rosenthal: Yes.

Stephanie: ... Um, to contribute to one research project or another. And then there's also iConquerMS.org, and they are doing those survey-based patient powered research network, doing really awesome work.

I highly encourage everyone to check those out. Again, we're going to put all of this in the link, so

no need to memorize it.

So, any final thoughts or considerations you'd like to talk about?

Dr. Rosenthal: No, I would just say, you know, if you are on the fence about research, to just do some more digging, get more information, and then just try something out, see, um, how it goes for you. Um, I think that it's just going to help us to provide better care and help you as a patient and your peers to receive better care and give us the all the opportunity to learn more.

Stephanie: Absolutely. Thank you so much for being with us here today. We really appreciate your time and your expertise.

Dr. Rosenthal: Thank you. It's been a great, uh, great time. Thanks for having me.

Stephanie: In the description of this podcast, you can find resources, programs, and more information on what we've talked about today.

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Lastly, we'd like to thank all of our generous sponsors for their support of this episode. We couldn't do it [(16:00)] without them. Until next time, be well, and have a great day.

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