Episode 87: Dr. Rhonda Moore

Intro (Lisa Meeks)
Doctors with disabilities exist in small but measurable numbers. How did they navigate their journey? What were the challenges? What are the benefits to patients and to their peers? What can we learn from their experiences? My name is Lisa Meeks, and I am thrilled to bring you the Docs With Disabilities podcast.

Join me as I interview docs, nurses, psychologists, OTs, PTs, pharmacists, dentists, and the list goes on. I'll also be interviewing the researchers and policymakers that ensure medicine remains an equal-opportunity profession.

TRIGGER WARNING (Lisa Meeks)

Hi, this is your host, Lisa Meeks. In this episode we touch upon sensitive subjects that might be distressing for some listeners and readers. Please be aware that the content includes discussions about death during COVID-19, the loss of parents, and instances of medical injustices toward women of color.. Your well-being is our priority. If these topics are triggering or upsetting for you, we encourage you to consider seeking support during the time you engage with the content or choose to skip this content overall. Take care of your emotional well-being, and prioritize what feels right for you. Now, on to our episode.

Narration (Jasmine Lopez)
Greetings and welcome back to the Docs with Disabilities podcast. Today, we have the pleasure of hosting Dr. Rhonda Moore, a medical anthropologist and program officer at the NIH. In this episode, Dr. Moore openly shares her experiences grappling with chronic pain, along with her diagnoses of autism and attention deficit disorder, all within the context of the COVID-19 pandemic.

She delves into her personal journey, recounting how she turned to theater classes to cultivate confidence, and she discusses how these experiences, coupled with her encounters with chronic pain and disability, have profoundly shaped her professional trajectory. Dr. Moore also sheds light on the intricate challenges faced by Black women in navigating the healthcare system. As our inaugural guest with an autism spectrum disorder diagnosis and a program officer, Dr. Moore's presence amplifies the diverse narratives within the medical and STEM community. The episode kicks off with Dr. Moore introducing herself, setting the stage for a powerful exploration of neurodiversity among professionals in these fields.

Rhonda Moore:

Hi, I'm Rhonda Moore. I'm a medical anthropologist and program director for the genetic counseling resource for the All of Us Research Program at the National Institutes of Health. I currently work in the office of the director. I live with chronic pain. I'm also autistic and have a diagnosis of attention deficit disorder. I've been diagnosed for the last three years. And so this has been a sort of new journey for me in terms of another type of story that I've been living with chronic pain. And I'm really grateful for the opportunity to talk with you today.

Lisa Meeks

So, you are actually our first person to be on the show that identifies as autistic. And I was so thrilled that we would have the opportunity to highlight someone working in STEM., that identifies as having a disability. You mentioned that you were more recently diagnosed, as being on the autism spectrum and with ADHD. Can you tell us about the journey to a diagnosis later in life?

Rhonda Moore:

I had a diagnosis of chronic pain early on in my life, but in terms of knowing that I was autistic, that came much later. I got diagnosed actually at the age of 52, after having symptoms for years, but I didn't really know how to place them. My brother is also autistic. But he, growing up, needed a lot more support than obviously I needed. I didn't realize the type of support I needed, and I also spent a lot of time masking my symptoms. My mother was also diagnosed later on in life as autistic, with also attention deficit disorder and so when she passed away, I was struggling with grieving that loss. And then I sought the help of a clinician just for grief management and also, decided that I would seek a diagnosis for autism and attention deficit disorder since it seemed to run in the family, having a mother and a brother, first degree relatives.

I sought a diagnosis because I was having some trouble managing symptoms. The traditional masks and strips that I always used weren't working anymore. I sought my diagnosis during COVID so it was really hard to find a clinician. And when I found one who worked with adult attention deficit disorder, adult diagnosis, it was just really, almost like, I got a renewal for my life because I was able to tell a different part of my story.

It was nice to find a clinician who could help me to not only manage symptoms, but also someone who could help me to understand this new facet of my identity, and not feel shame about my identity. Growing up my brother felt a lot of shame about being autistic. He was teased, he was bullied. And so, I wanted to enter this in the same way that I do my chronic pain diagnosis. I'm very open about it. I didn't wanna feel shame about it, and I also wanted people to be able to engage this new facet of my identity. So finding a clinician to give that support was really helpful.

Lisa Meeks:

Thank you so much for sharing. And I'm so sorry about the loss of your mother. I lost my mother during Covid, as well. And it was very difficult to find comfort when you're already in such a stressful situation and you can't see your friends, you can't hug people. It was an isolating feeling. Also struggling with having that person be a main source of support and with trying to figure out how to have the emotional response that you want to have, but maybe not maybe struggling to do that. I went through anger and grief and, just feeling, yeah, I think very, very similarly. Like, how do I go forward? And then the whole world was really crumbling around us, making it even more difficult.

So I wanna, if it's okay with you, I just wanna ask about that diagnostic process because people were not seeing patients in person, which I would think would make it really difficult for somebody on the autism spectrum even more difficult to diagnose, but to understand what's happening. When you went through this process, were you doing this remotely on Zoom?

Rhonda Moore:

I did it remotely on Zoom, and I also went to the person's office because she was seeing, for this type of diagnosis, it's important to be able to, on Zoom, you can see certain features, obviously, of people's emotions, and you can read them, but it's better to do that in person. And so she also made the option for me to see her in person so that I could also get the diagnosis 'cause it's a huge battery of tests, or, let me rephrase that. Three years later, it feels like it was a huge battery of tests, and that it went on and on and on. And so, I found her actually on Psychology Today. I'm not, I don't work for them. I'm not making an advertisement for them. It was just very hard for me to find a person who was actually seeing patients, whether they were seeing people virtually or otherwise. And then, I lucked into this particular clinician. She was seeing adult patients. She had an opening and that she was seeing people virtually and also, for a diagnosis, she wanted to see people in person. So, you know, we were in there with our mask on and then I took my mask off because I had been vaccinated, and just sort of, it went from there. But it was very hard because, you know, the first person I would've told about my diagnosis would've been my mother. And I'm also sorry for your loss too. It's hard. And it was at the time.

Narration (Jasmine Lopez)

Scripts play a vital role in supporting individuals with autism spectrum disorder (ASD) by providing structured verbal or written cues to navigate social interactions and daily routines. These scripts serve as invaluable tools, offering a sense of predictability and clarity, reducing anxiety, and enhancing communication skills, Ultimately empowering individuals with ASD to engage more confidently in various aspects of their lives. In this next section, Dr. Meeks and Dr. Moore discuss experiences of developing and using scripts and the intervention needed when scripts fail to remove barriers.

Lisa Meeks

So I'm gonna take you back. You mentioned that you know your scripts and, and I have to disclose, I worked with individuals on the autism spectrum for years. They are, oh, so near and dear to my heart, I worked with, mostly young males in the kind of undergraduate families too, college age, so 18 to 25, so many amazing stories of working with these incredible individuals and their families. And we would develop scripts, right? As a clinician and a support person, I would help them develop scripts to navigate their spaces. And so it, the minute you said, you know, my scripts weren't working, I was thinking, oh gosh, you know, I can imagine as we move through our learning continuum into our career and then start to advance in our career, there are more and more demands on us that are part of what we might call the unwritten curriculum. More of these social political landscapes of the office of the more interpersonal communication that happens with a myriad of different personality types, different types of people from different backgrounds. And it does become harder to script all of that out. But it sounds like you did quite well using these original, self-mitigating measures to start your educational pathway. Is that true?

Rhonda Moore

I didn't realize that I was using scripts at the time, although obviously in retrospect, you realize that, you know, your whole life is scripted to some degree. I wanted to do something because I noticed that I was a very, I was a loner. I didn't look people in the eye. Even though I had a forward facing student job, I just wasn't doing very well. So I took theater classes, one because I felt like there was a part of myself that was waiting to get out, and I didn't know how to do that, to the outside world. Also, as an African American, I felt that if I'm silent about everything, then I won't move anywhere in life. And so I took theater classes as a survival strategy, to learn more about myself, but also to learn more about how to project that inner self and create other types of scripts. So that helped me to really do that.

And I took communication classes because I realized that was a deficit in my background. So, 'cause I grew up with a brother who was very quiet. Our whole family was very quiet. We didn't have that many friends over because my brother was bullied by most of the people in the neighborhood. We were just very isolated growing up. And so I didn't really know how to connect with other people in a way that was going to be, that was going to lead to sort of longer or sustained relationships. And so I took these communication classes and theater classes and decided that was gonna be my major because not only did I enjoy it, but it also helped me to envision other types of scripts that I could use and engage in the real world.

Lisa Meeks:

Well, first of all, I mean, brava! Leaning into the communication and the drama classes. What a great way to address some of the things that can be more difficult, for someone that's on the autism spectrum. I think that was a brilliant intervention, if you will, without even knowing, because at that time, you didn't know that you were autistic. So, but brilliant intervention. And it sounds like it really helped you and probably continues to help you in most of your roles. So, you mentioned that at some point the scripts failed to work. What types of situations did you find yourself in that were more challenging?

Rhonda Moore:

I took a job in the federal government. I had been in a role for eight years at the FDA and you know, the great thing about the FDA is that you get into a habit of routines. So my scripts worked really well there. And, you know, I advanced along in my career there, and was enjoying the work. And then there was an opportunity to work in a more medical anthropology related role at the National Institutes of Health.

But the job was fast paced. You had to constantly create different types of scripts. And then my mother passed away. And, I found that the other types of scripts that I could create weren't the problem. It's just new types of interactions. I needed reasonable accommodations. And when I asked for them, they said, well, we can give you minimal reasonable accommodations; if it's outside of our group, we can't support those reasonable accommodations. So what I needed was, you know, I can't meet with people from nine o'clock in the morning until six o'clock at night with no breaks. I can't do that. I need breaks in between meetings. And what I was asking wasn't an obnoxious list of reasonable accommodations. They were just things that would help any individual living without a disability to function better in the workplace. But they couldn't support them just because they said so, because of the nature of the work. And so I found myself without my mother, in a situation where I needed support. The realities of the job were not going to give me reasonable accommodations that were supportive.

Music Interlude

Also, in addition to that, I didn't have a therapist at the time to help me to kind of understand this sort of what was going on with me. And I was stuck in grief. I just wasn't able to move beyond that. And so I felt like, you know, my scripts were a house of cards and they sort of fell to pieces, and I didn't know how to pick them up, even though normally I would just pick them up and create a new script. This was a script that I had not encountered, the grief that I felt for the loss of my mother, but also the fact that I wasn't getting reasonable accommodations in the workplace, and the routine was such that it was hard, it was gonna be very hard to accommodate what I needed. And so I started to look for another opportunity.

Lisa Meeks:

I'm sitting here just tearing up thinking, I feel so, I feel so much empathy for you. I know what you're going through and it is an impossible recovery. I feel at times we're going to live in grief, in moments of grief, I would say moments of joy and moments of grief, forever. For those of you who still have your mothers, please, please pick up the phone, call them, hug them. It's a loss like no other.

So understandable. Routine structure, these are the things that help everybody flourish, right? But especially individuals that are on the spectrum and having that, kind of, those guideposts, if you will. And so that loss coupled with the intense changes under Covid. And honestly, I'm sitting here thinking, and correct me if I'm wrong, but you know, before, you may have had some of that in between time because you were meeting people in person. So to get from meeting to meeting, there might have been some naturally built in time. But under Covid conditions, and, and I struggle with this, I know a lot of us, do it back-to-back, your Zoom room, Zoom room, to Zoom room. I'm gonna just say that's not good for anybody. But you have no time to process and you're constantly under this kind of sensory stimulation, overload of visual content, auditory content.

Rhonda Moore:

I'm in agreement with you. It was, it was so hard. And also I didn't see a way out of it. Like I mean, normally I can create a different script, but I was creating scripts just to have one-on-one encounters with clients cause I was in a program director job, and I could do the work, and I was doing the work and actually got, you know, rave reviews. But I was burning out because of that overwhelming sensory overload. And at the same time, I was grieving that sort of loss. And so I was trying to make sense out of nonsense because I didn't see a way to rebuild those sorts of scripts or that sort of structure that has sort of sustained me up until then.

And, that sort of 'water cooler' conversation that often happens in between meetings, I did some of that in my old jobs, not in quite the same ways that most people do, I just got to meet people in the office, got to know people in the office, but all I didn't realize just how supportive that is in terms of sustaining and under covid, all of that fell flat too. So I feel like under that time, it was a incredibly difficult time because I was also experiencing autistic burnout and didn't realize that I was experiencing autistic burnout, and emotional burnout just because of that the sort of aggregate of losses that had been happening and the lack of reasonable accommodation from meeting to meeting to meeting, which I agree with you, is hard on anyone. But when you're trying to struggle and navigate as an autistic person with attention deficit disorder, it's very, very hard to navigate those experiences. And that's why it's important to get the support that you need or try to get the support you need, in terms of a good therapist. It really makes all the difference in the world.

Lisa Meeks:

So that's a perfect segue into where I wanna go, because getting the diagnosis for so many people, it's been described as like having a weight lifted. Did you feel a sense of relief?

Rhonda Moore:

I felt a sense of awesomeness, actually. It was not only a relief, but I, it was a relief, but I felt supported in a way. I had felt weighted down just because I didn't know what was going on with me So I just assumed that I was the one who was broken. There was something going on that maybe this grief experience of grief had just caused me to shatter. And I have always believed that, you know, we are our stories and somehow that our stories are always fragmented, and then they kind of come together in this sort of beautiful, broader narrative. But I couldn't see an end to my story, which normally I could script to some degree. And I know that we're always living our stories, but what I found was it was incredibly hard up until that point, and then all of a sudden it was like a new lease on my story.

And I had also reached out to individuals in the autistic community, who had, you know, either been diagnosed many, many years earlier than I had, or who had been diagnosed as children, who were also women, and reached out to them and developed my own sort of external support groups, just because there were so many things I didn't understand and didn't know and didn't know about the language of the community. So it was really helpful at that time. So instead of staying sort of, more insular, once I got the diagnosis, I reached out. I had been reaching out to other people, but I continued to reach out.

Music Interlude

Being around individuals from the community, who were empowered, you know, who had been speaking out about being autistic, and also about the joys of autism, and also the joys of finding community in a, in a new way, at different facets and different points in their lives, was just incredibly empowering. It was empowering to me because, you know, I had spent most of my life, I have very few friends, and didn't have a lot of opportunities for friendships living, you know, growing up. And so it was an opportunity to have friendships in a new way, at a different point in my life.

Lisa Meeks:

You bring up such a good point, and it's one of my pet peeves, that individuals have the, what I call the media impression of autism, right? This very rote, this is, if you're autistic, you can't communicate, you can't look people in the eye. You can't have conversations. You're going to have a meltdown at some point. You don't want companionship. You're not interested in even sexual relationships or friendships, they're seen as a burden or extra work. And that has not been my experience.

I think that individuals on the autism spectrum are so stereotyped. You've talked about not making eye contact, not having many friends, but I wonder if we just take those two examples that you've given us, you know, the not having much eye contact, we can understand that it's a sensory issue. It's uncomfortable, but that doesn't mean that you don't wanna have friends. Would you say that growing up you wanted and longed for friendship, but maybe didn't have the skills to engage?

Rhonda Moore:

My parents were very protective because my brother was being bullied so they hyper screened anyone who potentially could have been a brother or sister of someone who bullied him. I think they were hyper protective, protective of my brother, and by default with the things that my brother couldn't do that I couldn't engage in, I think there were other issues in the home. They weren't particularly happy with one another either. So I think that it led them to sort of not support as much of the social engagement.

Through the theater classes, I learned to look people in the eye. I just decided that, people, at least in American culture, and this is sort of broader, sort of non-Hispanic white culture, tend to, if you don't look someone in the eye, they don't think you're trustworthy. And they don't invest in quite the same way emotionally. understanding that I tended to look people in the eye. I don't do it directly for long periods of time. I've learned to, I've sort of learned to compensate for that, so that people will realize that I'm trustworthy and that I have something to offer that's greater than what they would've previously thought. But I do think there is, a lot of stereotypes about the community that are really problematic. When I was first disclosed to people, there were people who were like, well, you don't seem autistic clearly you can't be autistic because, autistic, someone who's autistic is like “Rainman”, you know, almost a st when it comes to math. I said, well, I can barely add. So I'm not really great at math. I'm good at other things, good at pattern making, good at retaining memories of important facts. There's just things that I am good at, but I'm not good at a stereotype and no one's good at a stereotype.

There are a lot of misconceptions about the community that we still have to fight against and that we're not broken. That autism isn't something to cure or something to fix. People need support. They need reasonable accommodations. They need jobs because most autistic individuals and adults don't have jobs. So they need not only employment, but also meaningful employment for things people need that are outside of these sorts of stereotypes.

Lisa Meeks:

I was on the board of a few organizations that were doing coding and things like that, leaning into some of the perceived or real skill sets of this group. But in doing that and creating these opportunities for work, they were also creating a community, as an opportunity to socialize, where the way that you socialize or what you wanted to do was now the normative way to socialize and engage and, wound up being such a great resource for so many of our students. And then the community has just grown. I haven't been as involved when I moved over to medicine, but the community has grown so much, and I am just always so happy to see all of the connections going on, all of the groups, the advocacy.

Narration (Jasmine Lopez):

Engagement between people can vary socially and culturally by country and region, such as how Dr. Moore discussed the value of eye contact in the U.S. and its implications for autistic individuals. Stereotypes about people and the impact on true connection is powerful. Listen as Dr. Moore and Dr. Meeks describe their experiences engaging with others abroad and the noted differences from the U.S.

Lisa Meeks

We tend to reduce people, don't we? I mean, whether it's by race or your sexual orientation or your job description or your age. We are such a reductionist society, and I don't see this as much outside of the U.S. You mentioned something about this being very U.S. centric. I would say that it's fascinating to me. I've spent a lot of time in Europe this year; I actually lived there for a little while. And people don't ask you what you do for a living. They don't ask you, you know, kind of the stereotypical questions that we start with in the U.S. right? We wanna categorize you immediately in the U.S. who are you, what do you do? How important are you? How do you fit into my schema? And you go over to France or Italy or anywhere in Europe and people wanna know who you are, who you are as a person. It's a very different type and style of engagement and I found it really warm and just different.

Rhonda Moore:

I think it's really warm and wonderful. in terms of the friendships that I've made, and I'm in agreement with you. I spent some time in Brazil and I've spent some time in the U.K. I did a hospice rotation in the U.K. and people were really interested in who you are, what you like to do, what are some of the things that you would like to engage in. I mean, it was a totally different conversation. And it was, it was refreshing because in DC, the first thing someone asks you really is what you do for a living and how you can help them or, or how they can connect with you, in terms of your work. And it's refreshing that someone wants to know who you are and what you all might do together, as human beings. So that human to human connection is really important. It makes a difference.

Lisa Meeks:

I think we've lost getting to know one another, right? Just on this human level. And that connection, whether you identify as autistic or, or not, that connection is so important to just our development as humans.

Music Interlude

You connect a lot of people now in your, in your work. Tell us about your role. I love your role.

Rhonda Moore:

I currently work with the All of Us Research Program., and the goal of the program is to recruit a million or more people, around diverse metrics. So representing people from underrepresented communities, within the whole framework of the program. Community engagement is a huge proponent, a huge part of the program and also health equity is one of our metrics across the program. So it's a really beautiful program. It's one of the most ambitious programs 'cause it's in genomics, and soiIt's NIH's Precision Medicine Initiative. I came to the program, there was a colleague of mine and friend who also worked at the FDA. And when this job opportunity came up, he had, I think, recommended me as somebody to talk with, but my current supervisor had already decided that I was someone she wanted to interview. And so, the interview process was much easier than a lot of NIH interviews. You know, when a job feels right, everything else flows differently. I didn't ask about reasonable accommodation during the interview process.

And so currently what I do is I'm a Program Director for the genetic counseling resource. The genetic counseling resource is responsible for returning genetic results to participants. We believe participants are our partners, and so we work with individuals as partners, either as participant ambassadors. It's a part of our framework. It's just been a really wonderful component of the program. And as a person who's autistic, when I first came on board, I mentioned during my interviews that I was autistic. And that, you know, part of the reason I wanted to join this program is because of the focus on diversity, the focus on equity, the focus on including participants as partners. And so that was part of the reason that I took this job, is so that I could be part of this wonderful program that is going to make a difference in people's lives. Not only people who look like me as an African American, but also people across the United States, from all different diverse backgrounds, sexual and gender minorities, people with disabilities, people living in low income situations. And so it was something that was really inspiring for me that, here's this part of NIH, that's not only thinking about doing that, they're actively doing that.

Lisa Meeks:

That's amazing. So first of all, we need more representation. So the idea of the All of Us program is needed. We don't, you know, we talk about how we have precision science, but we don't. We are missing so much information. So it's a really important program. Tell us about what happens when someone has a result that maybe carries a little bit more weight or surprise for them.

Rhonda Moore:

The genetic counseling resources are the ones who return the results. I'm the Program Director. So basically I am supporting that program, making sure that they have funding, certainly making certain that they're meeting sort of designated milestones and deliverables for the program. When someone, has a hereditary disease risk positive report, which is the report that, say for instance BRCA1 mutation, the genetic counseling resource, the, the person, doesn't go to the generalist platform, they can't download a report. They have to have support while they're getting this particular result. They'll know that they have a result and that they need to talk with a genetic counselor in order to get the result. And so, we're not letting people go into these sorts of situations without support. They talk to a genetic counselor and anyone across the program, even if you get a hereditary disease negative report, you can talk to a genetic counselor. It's just that in terms of downloading your report, you can get the support from the genetic counseling resource. So people aren't getting a positive report with no support. So it makes a total difference in terms of their experience, and that they can ask questions about whether or not they should share this with their physician, or the clinician or should they share it with family members? And if, and also, they could be on the line when they talk to the family members too, the genetic counseling resources on the line when they do that too. So it's a whole experience of support so people aren't sort of hung out to dry and they can come back with as many times as they have questions, they can come back and talk to genetic counseling resources. And these are accredited, genetic counselors. And, we have genetic counseling in Spanish as well as English, as well as medical translation and 200 plus supported languages.

Lisa Meeks:

Wow. And, you know, genetic counselors, we don't talk about them enough when we talk about our healthcare workforce but they're really important, especially when we're talking about disability, because they have a unique responsibility to not perpetuate the stereotypes of specific disabilities. And they are going to be delivering this information to patients who only have what society has told them, right. About any particular kind of disorder and the quality of one's life, if you indeed are going to develop this disease, or you're going to have this condition. I don't know if your group has done training or awareness or kind of anti ableist exercises towards the goal of being able to do this work and also not, I guess feed that fear.

Rhonda Moore:

Well, within all of us, there's an E-D-I-A, which is equity, diversity, inclusion and accessibility, coordinating committee. And so the committee is responsible for making certain that across all the whole program that, you know, decreasing ableism, increasing enhancing diversity, equity and inclusion across all programs. And we're currently undergoing training, to decrease racism and enhance our understanding of structural racism, but also methods to decrease structural racism across the whole program. So it's sort of built into the equity, the EDIA coordinating committee, is coordinating to make certain that, anti ableism, decreasing structural racism is across all aspects of the program. So we are doing training as well as making certain that across all programs that health equity is sort of a center component across all the programs.

Narration:

Throughout history, Black women have faced systemic biases in healthcare, particularly concerning access to pain medication and the misconception that they possess higher pain tolerance. This deeply ingrained stereotype has resulted in inadequate pain management for Black women, contributing to a long-standing disparity in the quality of healthcare they receive. The historical narrative is fraught with instances where Black women's pain has been dismissed or underestimated, leading to prolonged suffering and compromised well-being. Follow along as Dr. Moore describes her journey with chronic pain and her experiences attempting to gain equitable access to appropriate medical care.

Lisa Meeks:

I wanna go back to another part of your identity. Tell us about living with chronic pain.

Rhonda Moore:

I didn't grow up with chronic pain. I noticed that I had pain growing up, but I, and I had, extreme joint hypermobility so I was always injuring myself, but I didn't, you know, read that I had pain because I think part of, you know, as, as a kid, I just wanted to be outside running, getting injured, doing all these things. And, I didn't take it that there was something that potentially was wrong with me until I went to see a rheumatologist.

I had a very bad car accident, my car flipped. And I noticed a night and day difference in my life in terms of chronic pain. And I got a diagnosis of fibromyalgia, but I also had a diagnosis of Ehlers Danlos. and so I have, EDS, hypermobility syndrome. And so, I noticed that I was just living with chronic pain after that. So my experience with chronic pain, I had experiences of it and I was always injuring myself. But I didn't recognize that I was living with a severe sense of chronic pain. But after that car accident, and after that diagnosis and, and speaking with a rheumatologist, I got another diagnosis and I've been diagnosed since I was 28, and I'm now in my mid fifties. Every day, I'm taking medications for chronic pain. I found that it increased my activism around chronic pain. I wrote my dissertation on chronic pain, and the experience of suffering. I also have edited several books on pain and disability, because I think it's such an important area, and over a hundred million people in the US live with chronic pain. It's an invisible disability. Every day, I have chronic pain, but I say that pain doesn't have me because there's so many other things that I try to focus on. I took a lot of meditation classes just so I could learn to distract myself from the pain that I live with. Do I have bad days all the time? But do I have great days? I do have great days. So, I try to focus more on those days.

So, I have learned to just sort of distract myself from the pain, but I'm not always successful. In fact, most days I'm not successful. But, I had tried to focus on other aspects. I'm, I'm married, so I have that support from my husband, and I've had the support for the last 12 years, that I've been with him.finding out that I was autistic after having chronic pain, I was like, well, you know, at least I know who I am and I'm learning more and more about who I am. All of these, different facets of identity have made me stronger and have made me engage in the world in a different way, and I wouldn't be the person that I am without it.

Lisa Meeks:

Yeah. And in many ways we get to, we're, we're both in our mid-fifties, and that's an empowering time in your life, because on the one hand, gonna be honest, you do not care anymore about what anybody else thinks, and you won't allow people to define you, but you also have this privilege of defining who you are. You're like, okay, I now know I only have so many years left. What am I gonna do? What do I want to be? And the power to know that you can, and, and certainly for you, Rhonda, you've, you've been through this myriad of professions as you've gone through your professional career pathway, you can do anything you want to do. So there's that power in knowing that, if this isn't bringing me joy anymore, I can do something else. I can accomplish something else.

Rhonda Moore:

I'm in, I'm in agreement with you on that. I do think that there's something that in my thirties, I was much more anxious about finding, not only finding a job after doing fellowships and then being in, a sort of non-traditional medical career sort of made me go, well, where am I? Where do I fit? 'Cause I didn't necessarily fit into a traditional medical trajectory at the time. And so did I wanna go into the government and do public service, which I'd always wanted to do that I wanna teach at a university. I didn't know which one I wanted to do, so I flipped a coin. I don't recommend doing this, but I flipped a coin at the time, but I was really anxious about getting in the government, getting that really great health insurance because I knew that that mattered for somebody who was living with chronic pain. and getting that sort of right job and trying to navigate toward that right job. So that really mattered to me and having health insurance made all the difference in the world, just in terms of having access to doctors, having access to the right type of subspecialties that I needed and because I could self-refer to many of these, I felt more empowered and more in control.

Music Interlude

Rhonda Moore:

When you're an African American woman, when it comes to chronic pain, people assume you don't have pain. people also assume that your pain, that doesn't matter and you, you get dismissed. Really one of the challenges of living with chronic pain is knowing that there's a whole sort of field out there that denies that you have that pain experience. So I have to say that I was fortunate because I had just had a car accident, after which I got a diagnosis of fibromyalgia and I was able to get very aggressive and good pain medicine.

But before that, when it came to Ehlers-Danlos I wasn't able to get the type of pain management that I needed throughout my whole life. And I look at it retrospectively, is it because I was an African American that I couldn't find a doctor for Ehlers-Danlos which is a relatively rare disease. So there's that sort of rare disease sort of factor that's part of it. Or did I somehow, was it something that I, some part of my identity that people were denying in terms of pain? I did have a situation when I had fibroids in the hospital and I had demanded pain, good pain management before. And when I said I demanded I had set up a whole kind of pain clinic before to discuss all of my unique pain concerns. And because I know a little bit about pain, they thought that I was seeking pain medications for an abdominal surgery. And I was trying to help them navigate pain medicines that I was somehow that I knew would not work for my type of pain that I had had cause I've studied my pain for many years, and instead of them recognizing that I understood my own experience, they thought it was pain seeking when I had just had an abdominal surgery.

And so I think that many African American women have that situation where their pain is ignored or that it's not validated, and I don't compare it to, um, you can't compare it to what say non-Hispanic White women would experience because we have such a history in this country of discounting the pain of Black women. In fact, it was discounted so much that early anesthesiology was founded on doing sort of abdominal surgeries on Black women and other types of surgeries without anesthesia. And so we have a whole field that's created on denying a whole subgroup of having pain. So how do you disperse that? How do you somehow detoxify that sort of history? It's gonna be, it's gonna take a long time.

Lisa Meeks:

You're coming to the space with some medical background and an advanced degree and being able to advocate for yourself. Right. I always think about the people who are coming without that advanced degree or those credentials and, and that knowledge of medicine. It's always shocking to me how dismissive the medical community can be when it comes to pain or things that we can't see. And I think for many people in the chronic health space that is so terrifying to them is just not only being dismissed, but then not even receiving help for this medical need which can be really hard.

Music Interlude

Lisa Meeks:

Well, we're coming to the end of our time together, and as we do with every single podcast, we have the interviewee give advice to people that are in the pathway to the profession. And I'm so excited because like I said, you are the first person that identifies as autistic that is on our show. So thank you again. But also, you are the first person that is a program officer. I think that so many people don't even understand that this is a potential career path to being part of the scientific community to contributing to medicine. So with that, could you give a little bit of like, why should people go into this work being a program officer, and then advice for getting there for somebody that has a disability and may maybe thinking, gosh, this is a great pathway for me, I get to contribute to medicine in a way that I hadn't thought about?

Rhonda Moore:

My career, as I mentioned, is a non-traditional medical career. I've been exposed to medicine obviously my whole life, but also, in terms of my dissertation research, I worked with people and postdocs I worked at medical schools, whether it was Stanford Medical School or MD Anderson Cancer Center. So, I've been sort of immersed in medicine. At the same time I'm not a physician or, and I don't treat patients. But what I love about being a program director in, and this sort of ties back to sort of what I said earlier,medicine is a story, and you're helping to create a story that is much more diverse, that helps people, that helps people from underrepresented backgrounds,in underrepresented communities.

So you're helping to not diversify genomic medicine, which has historically not been that diverse. Polygenic risk scores are sort of based on representative samples and the rep, the samples aren't representative of the broad diversity of our nation. And so the work that I'm doing now is helping to sort of broaden and level that playing field so that people will have better access to medicines that treat all of us, not just some of us, and so that's exciting. In terms of a non-traditional career, or even a traditional career, I think being a program officer is you're able to help people tell a different story and help medicine to transform itself into a much more diverse, equitable, and inclusive and accessible field. NIH has a lot of programs right now thanks to this current administration that are focused on equity, diversity, inclusion, and accessibility. And not only doing that for funding opportunities, but also trying to create a much more diverse workforce in the biomedical sciences. And so one track that I would find is informational interviews. That's been incredibly helpful for me in terms of talking to people from different backgrounds, whether someone had a PhD like myself or whether someone had an MD, talking with them about their whole career trajectories, because everyone's story matters. It's just trying to find whose story is much more similar to your story so that you can find that sort of in, but also learning more about the environment, whether or not an environment is supportive of accessibility, supportive of reasonable accommodations. I did that through informational interviews, and that was incredibly helpful. Also, talking to people at, at all levels of the organization.

I don't just talk to people at my same level. I talk to people whether they work, as an administrative specialist or whether they work as the head or director of a unit. I talked to all different people just so that I could learn more about the background because how someone treats someone who's at the lower level of the organization is going to be how they'll treat me. Don't, not to be afraid to move if an organization is not as supportive as you need or if the job is not where you wanna be in terms of your spirit. My spirit is really wanting to do work that is expanding accessibility and inclusion and diversity for organizations. And so that's what I chose to make it as my mission within the government. And so I moved around quite a bit just to make certain that I would be able to fulfill what, what is my life for. And it's borne fruit. I spoke a couple weeks ago, at the White House talking about African American communities and autism. And, I wouldn't have been able to speak on, on behalf of myself and on behalf of my current role and the transformational role that it's had in my life if I wasn't at this particular job. So other opportunities will come to you, if you're able to move around in the government and once you're in, you're able to move around and being a program officer is being a shepherd of different types of ideas and certain different types of portfolios. And every time you take another job, you're learning a lesson that you can build into that next portfolio.

Narration (Jasmine Lopez):

Dr. Moore's interview serves as a pivotal shift in the podcast, serving as the inaugural guest with autism spectrum disorder. Her participation sparks a crucial dialogue on the unique experiences and challenges faced by individuals on the autism spectrum aspiring to pursue careers in medicine. We extend our gratitude to Dr. Moore for her unwavering openness, dedicated commitment to science, and sage advice for those aspiring to join the biomedical workforce. In our ongoing commitment to fostering neurodiversity in STEM and Medicine, we invite individuals with diverse perspectives to share their stories by reaching out to us at docwithpodcast@gmail.com or through our website.

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End music

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