



Can Do MS Podcast Transcript

Race, Representation, and Redefining What Sick Looks Like

Episode 49

[music]

[(0:06)]Samantha Balistreri (Can Do MS Podcast Host): Hello, and welcome back to the Can Do MS podcast. I'm your host, Samantha Balistreri.

For episode number 39, we're thrilled to have Victoria Reese with us today. Victoria was diagnosed with relapsing remitting Multiple Sclerosis in 2012. After becoming a leader in patient advocacy, Victoria founded We Are ILL as a means to address the profound void she discovered an MS coverage, awareness, and community for Black women and women of color.

Victoria, thank you so much for joining us today.

[(0:43)]Victoria Reese: Thanks for having me. I'm excited to be here.

[(0:46)]Samantha: Can we start by having you speak more to the differences you've noticed between the MS experience for Black people and people of color?

[(0:55)]Victoria: Sure. Uhm, so what we know now from uh, medical research that's been done and shared broadly is that the Black experience uhm, symptoms of MS, uhm, affect Black people or Black patients living with MS more severely, so on a physical level, we are dealing with this illness- We're having just the overall different experience, uhm, symptom-wise, which we know with MS is so unpredictable, but it's also such in- a broad range of symptoms, you know, that sounds just unbearable when you- when you think about it. Uhm, [clicks tongue] and then, overall, uh, when you're doing your research marketing-wise, uhm, there still isn't as much uhm, as we sh- should see of a presence of Black people in marketing materials, or at least, culturally competent marketing materials that are specific to Black people. I think that that is a- I know that that is a huge reason why I'm here today, just being- feeling left out of the narrative, you know. The Black experience is an isolating experience, or at least it was for me. Things are a lot different now, which I'm very proud to say, uhm, but I think that the only emotional side, it could be a bit isolating if you're not finding research about yourself, or you're looking to learn about your diagnosis and you're feeling that you're

left out of that story. Uhm, and it's important because it can affect the trajectory of your illness.

[(2:34)]Samantha: Yeah. No, thank you for explaining that. That makes a lot of sense. Uhm, a lot of people can really relate to your self-empowerment. How has sharing your story help you?

[(2:43)]Victoria: Well, uhm, sharing my narrative first was liberating. It was freeing. It- it set me free of some of the worry that I had. I was young when I got diagnosed, and worried about my future, physically, emotionally uhm, [clicks tongue] worried about what my future looked like, and sharing my story from the beginning, uhm, it was like my own personal therapy in a weird way, but it's been liberating and it's been healing, and uhm, it's- I don't know. This has been a wonderful- twisted, wonderful experience [chuckles] because it was a negative thing that I was able to turn into a positive thing, because sharing my story helps other people and encourage other people, inspire other people, but most importantly, it brought people together, and I think the community is what we were all looking for. Uhm, so yeah, it's- I don't know. It's been a- I can't really put it into words, but it makes me smile because I didn't know that sharing my story would get me here.

[(3:57)]Samantha: Yeah. No, that's- I don't know, sticking to you in quite a[?] long ways. Uhm, there's a couple other things that have helped you take control of your life with that mess. I know you're very passionate about self-advocacy. Tell me a little bit about why that's so important to you.

[(4:09)]Victoria: Yeah. So [clears throat] I call myself a professional patient [chuckles], and I started saying that jokingly, but now, I kind of use it daily. Uhm, I said a professional patient because the average person, if you just get the common cold, you know, you- you go to your primary care physician, what, every six months, and that's about it. You go and, you know, they listen to your heart, look in your ears, and you're kind of good. Uhm, and if you do get a cold, you may not even go to the doctor. You're just figuring it out. You go to CVS and you go get your medicine, and you figure it out. Uhm, that's, to me, the average person. Uhm, and I also will say that's the average person, even when they need to do more. [chuckles] They need to go to the [inaudible], but the average person, it's really not, like avoiding it for multiple reasons. [clicks tongue] But for a patient living with MS, you know, it's important to become a professional patient. Not all of us are, but it's important to become a pre-professional patient because you go to the doctor so often, you have this broader healthcare team, you have these very stable uhm, [clicks tongue] appointments and tests, and blood work, and uhm, calls with insurance, and authorization forms, and uhm, butterfly needles if your bl- your veins are tiny, and, you know, you just have this- this system, this ecosystem, that's new for you, and you've got to get on board of knowing what's going on because it's so much, it can get ahead of you and your- you can get lost in the sauce, [chuckles] and if you don't know the terms, then you're really not having a real conversation with your doctor,

if you don't really know the terms they're talking about. If you're not asking, "What- what does that mean?", uhm, you don't really know because it's so many medical terms, and it's like, "You're not a neurologist. You're not a MS specialist." You- you're not expected to know these things, so that's why you- you know, you do have to do your own research outside of your appointments uhm, and ask the right questions.

So uh, the self-advocacy comes in, [clicks tongue] uh, I think, first and foremost, of understanding your MS. You got to understand it. It takes a while, too, because emotionally, you know, uhm, myself, personally, I wasn't able to really read more than a paragraph for a few months. And then, I'm like, "Okay, now, I can get to the second paragraph. Okay. Now, I can get to this article," because it was a lot to take in, uhm and it's- it was scary. Uhm, [clicks tongue] so the self-advocacy aspect of it is really knowing you're owning your health and being an advocate for your health. If your doctor isn't listening, get a second opinion. if you're- if you would like to try a new therapy and it's not working, speak up, say what's going on. You know, that's self-advocacy, uhm and that's why it's super important because I'll use that word, trajectory, again. It could really alter the trajectory of your uhm- your diagnosis.

[(7:19)]Samantha: Yeah. That makes a lot of sense. I think being a professional patient isn't something you're necessarily asked to do, but you- it sounds like you really just jumped into that and made a lot of great points for why others should consider being advocates for themselves, as well. Something else that helped you take control of your life with MS is building community, which you've done fantastically. Can you talk about the community you built?

[(7:43)]Victoria: [clicks tongue] Yeah. So uhm, [clears throat] I built a community called We Are ILL. Now, a nonprofit organization, but it started as a teeny, tiny uh, awareness campaign that was on social media. Uhm, I mentioned that when I was diagnosed, I took to social media to share what I was dealing with, and that had- I had been diagnosed. And, I, by profession, I'm into marketing and social media and content, so I didn't set out for it to be like that when I first posted. I was just being a normal, honest, direct self on social media.

[(8:23)]Samantha: [chuckles]

[(8:23)]Victoria: And then as some time passed, I still felt alone and uh, no community. [clicks tongue] Uhm, and I realized, like, the things that I was seeing seemed bleak and sad, and somewhat depressing. Uhm, you know how you see those commercials about pets and they're not being taken care of and it's [crosstalk] a sad music? I always joke about that. It's not funny, but how those commercials, like, make you feel, I felt like that's how marketing materials and- and Instagram pages were- that were supposed to be educational for MS, but also supposed to be uplifting, it- and it also was supposed to spread awareness, but if it's, like, sad. People aren't sharing this sad post. People aren't- they're just scrolling by and maybe unfollowing because it triggers them. So I was like, "I have to flip this." Uhm, so, I just

uh, flip the ill into like, cool, like dope, and uhm started this awareness campaign, crazy content, and the goal was to build community. It was to find my tribe, and it works. People started- but the funny thing is the other MS patients or other Black uh, women living with MS, they didn't originally come to me. What- what happened and[?] the- the beauty of it is, I just opened my mouth to whoever was listening, and then when I opened my mouth to whoever was listening, they remembered and associated me with MS. And then maybe a year or two later, or whenever, they would say, "Oh, my cousin just told me they got diagnosed with MS. Can I connect you to? Can I send your information? Can you talk to her?" So then, it was like this domino effect that came later, but it happened, and my community started to form. Uhm, and once they start to form organically, then I'm like, "Okay. Everyone who's reaching out to me is literally saying the same thing. They've never met another Black person with MS or a Black woman with MS, or whatever, or someone as young as me with MS." So, I'm like, "Everyone's saying the same thing. We got to do something. We have to rally together. We need to [chuckles] like, form a girl group or something."

So that is when I created an online support group, and today, we were[?] very strong. A lot of people were st- strong in numbers and we've got different communities and different social media platforms, uhm, and we're constantly growing, but building community has been so important because we've found each other. Uhm, I met older women that had- had- uhm, older Black women that have had MS for 20 years and literally have talked about- they've been alone for all these years, just navigating alone all these years. Their family doesn't understand them, their doctors understand, but don't- can't relate because they don't- they're not a patient, uh, and they just been alone and they had never met another Black person, either, with MS, ou- outside of the few celebrities that have publicly said that they have MS, as well. Obviously, they don't know those celebrities.

[(11:25)]Samantha: [chuckles]

[(11:25)]Victoria: So they've been alone for all these years. So, the community aspect has been life-changing. I found my sisters, I found my people, and we've just been figuring things out together and rallying together to make change in the space.

[(11:39)]Samantha: That's really incredible. You've touched a lot of people's lives and built a community not just for yourself, but for a lot of other people.

[music]

All right. Hang out with us. We're going to take a quick break and when we get back, we'll talk with Victoria about what We Are ILL is doing in the MS community.

[music]

Life with MS is full of firsts. The first time you hear your doctor say multiple sclerosis, the first time you go on a date after being diagnosed, the first time you decide to disclose your MS to your employer, Can Do MS is here to help you navigate this uncharted territory. Join us for a take charge on May 20th and 21st to meet other people in their early stages of life with MS and get personalized guidance from leading professionals. Visit cando-ms.org/take-charge to learn more and apply.

[music]

And we're back. So Victoria, what should MS organizations be doing to meet the needs of the Black MS community?

[(12:54)]Victoria: [clicks tongue] Yeah. I think that everyone is doing a really good job right now of trying to connect with the Black community, right? Uhm, I have to say that in 2022, considering the things that have taken place in society in 2020 or 2020 uhm, with racial injustice, I do have to say that some people are late and some people jumped on the bandwagon and jumped on the trend of trying to connect with Black people. I do have to say that. So it's very hard to beat out the fluff of who's doing it because this is what most organizations or it's the right thing to do, versus organizations and companies that are doing it because they know that it needs to be done, and that that inclusion is important in acknowledging the exclusion. Uhm, so it's very hard to decipher between the two, but I guess time will- time is the only teller of that.

Uhm, what I think they should do, I think when it comes to building community, I'm learning, myself, uhm, as I do it, but uhm, what I do know is that it's a process and it's done in phases. And the first phase is acknowledgement, so I think a lot of people have acknowledged uhm, or tried to acknowledge [chuckles], at least by even creating content that is specifically targeted to that community. But I think the next phase is through getting to know the community, uhm, and that isn't just, you know, creating some content that says some African-American in the subject line, [chuckles] and or Black people in the subject line.

It's truly, truly, truly, particularly, I guess, starting advisory boards, uhm getting out in the community and seeing what the Black community is dealing with. And it's not just about how MS affects uhm, Black people because that's the first layer, obviously. But I think in order to truly connect with the community, you would have to be in the community. You have to go closer to the community so that you can see the other things that affect their lives, on top of having MS because if affording healthcare is a thing, then that's not just about how your MS symptoms affect you. That's your access to care, you know, and health equity issues, and things like that. So you've got to really uh, get into the community uhm, and not just say you're trying to serve a community. Go out into the community, be a part of the community, do things for the- for the community and for the patients.

People have started to carve out a lane for content, so including the Black community and content so that uhm, they can be educated and- and resources are available, but I think the next phase would be true, authentic connection.

[(15:57)]Samantha: Yeah. Go see who's in your community and what you can do to help. What is We Are ILL doing to redefine what sick looks like?

[(16:05)]Victoria: Yeah, so [chuckles] uhm, we are- so re- Redefining What Sick Looks Like is our tag line and it- it's- it's layered. So when I started saying it, I was like, "Okay, I'm redefining what sick looks like because it is not just some of the- and I don't want to say popular, but some of the more well-known illnesses." Uhm, a lot of- in the Black community, at least, we're affected by a lot of- disproportionately, by a lot of different illnesses, but let's say diabetes or breast cancer. Those are some of the uh, health communities that are uhm, [clicks tongue] in the forefront, and people obviously know about. But MS hasn't been in the forefront of something that disproportionately affects Black people or Black women, specifically. So, it's kind of like, sick looks like this, as well.

The other- [clicks tongue] another layer is uhm, MS is commonly associated or connected to being disabled, in a wheelchair, things like that. So, MS is also able-bodied, as well. It looks like me. I'm not in a wheelchair. I don't have a cane. Uhm, that doesn't mean that on some days, I don't or that I ever- that I won't ever, at all. It just means that it looks like both. It- it's- I'm reshaping what you think I'm supposed to look like, or MS- and MS patients are[?] supposed to look like. Uhm, [clicks tongue] obviously, [chuckles] due to race because that's why we are here, we're specifically catering to Black community and Black women. Uhm, uh, MS isn't just for White women or White people. It- Black people get MS, too. So I'm redefining what sick looks like in that way.

Uhm, and then also, last but not least, age. MS is not just for older people, younger people get diagnosed, as well. So it's a very layered thing, but that- in all of those ways, that is how we are redefining what sick looks like. Uhm, and specifically to underserved communities, like the Black community, uhm, we have a lot of things in store. Our primary goal is community, building community, fostering and cultivating that community, uhm, and really da- listening to the community and understanding how to truly serve them. So that's just a constant connection, uhm, education, and making resources available, not just making resources available, but making our community aware of the available resources because there are plenty.

Uhm, and then, we'd love uh, in the future- in the near future to really do more in-person things. We've been- we came alive or we're birthed as a nonprofit organization right before the pandemic uh, started, so we've been in a virtual setting, which has been hard, but really, truly, truly, like I mentioned, getting out into the community and being present there in the physical form will be amazing.

[(19:01)]Samantha: [clicks tongue] Yes. I hope that is in store soon for- for you in We Are ILL and Can Do MS, and all of us. [chuckles] Uhm, yeah, I think you- you brought up a lot of great points there. Multiple sclerosis is a hugely variable disease so we need- it's important to- to recognize that and to display that. So, thank you for doing that.

Uhm, finally, what can someone do today to better navigate their MS and thrive?

[(19:28)]Victoria: I think first, we, as people, and definitely, we, as people living with MS or any illness, actually, we've got to really pay more attention to the emotional aspect of things. Uhm, I think that's also trendy in society. [chuckles] Emotional wellness. We've got to take a step back and really focus on the emotional [clicks tongue] aspect of being diagnosed with anything. It's a lot. When you get diagnosed with anything, the word "diagnosed" is triggering. It's heavy. It's- it can be life-altering, depending on what your diagnosis is, and I think that we've got to take a step back and pause, and really accept what- it's going on, figure out how we want to move, you know, after, like, do you want- do you need a moment? Do you need time to set back from- I'm just gonna throw it out there, like social media, like, take a step back from that. Take a step back from work. Take a step back from going to girls night every weekend, or something like, "Do you need a moment to really be to yourself and accept what's going on, and how you're going to navigate your- how you handle it emotionally before you have to share with other people?" Uhm, healing and coping, there's stages to coping. And even if you are a strong person, which I think a lot of Black women, we have this Superwoman complex where we are forced to be strong all the time and be head of household, and other things, we keep going. We keep pushing, and we are strong, but a little bit too strong sometimes. And it's important, and I'm an advocate for taking a pause and really accepting what's going on. And I think there's different uh, pit stops you make.

I am not- because I'm able to talk proudly and publicly about my MS or being diagnosed with MS doesn't mean that I'm on the other side of coping and healing, and all of that. I take pit stops. That is helping- that will help better navigate your MS if you first get your emotional wellness in check. Make sure you're good. Make sure you're healing. Make sure you're accepting what's going on, and make sure you're making a decision on how you are going to move now that you have MS. Not literally move, but [chuckles] how you are going to navigate, I guess, with- now that you've been diagnosed. Are you going to be [clicks tongue] sad about it for the rest of your life? Are you going to not, like, help yourself and learn, and educate yourself on your illness so that you can live your best life? Are you not going to explore all of the uhm, therapies out there and understand them so you understand what it's like to take them and all of the side effects, and all of those things. Are you- are you not going to do that? Or- or, you know, are you going to be on top of it and really say, "Okay. I have MS, but MS does not have me." You got to choose what side you're going to be on, uhm, and take your time, but you gotta choose.

[(22:46)]Samantha: Yeah. That's another really great message. I think our own mental health is extremely important for- for us, and something that I think people are starting to focus more on, like you mentioned, uhm, and I think that's- that's a great thing.

Well, Victoria, thank you so much for joining us today on the Can Do MS Podcast. It was a pleasure to have you and hear your story and experience, and what you're doing for your community.

[(23:10)] Victoria: Thanks for having me.

[music]

[(23:22)] Samantha: That's it for today's episode. I'm your host, Samantha Balistreri. Thank you for tuning in to this episode of the Can Do MS Podcast.

Not only do we want to thank our listeners, but we also want to thank our sponsors for their generous support. Thank you to EMD Serono, Sanofi Genzyme, and Genentech for making this episode possible.

We hope to see you next time on the Can Do MS Podcast. In the meantime, head over to our website for more great resources at cando-ms.org.

[END]

These podcast episodes are possible thanks to the generous support of the following sponsors:

