



Rewriting the Narrative: MS, Equity, and the Lived Experience of Black Women.

Presented by:
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Hi everyone. Welcome and thank you for joining MSAA's live webinar, Rewriting the Narrative: Multiple Sclerosis, Equity and the Lived Experience of Black Women. This program is part of our 2026 Our Voices educational series. It is presented in honor of Black History Month, and it was made possible through the support of Biogen, Novartis, and Sanofi. Tonight, we are joined by MS Specialist Dr. Heidi Crayton and lived experience advocate Dawn Morgan.

Together we'll explore both the clinical perspective and the personal experiences of black women living with multiple sclerosis. My name is Yahaira Rivera. I'm senior director of health education and healthcare relations at MSAA, and I'm honored to be your host. And I want to make sure that you are familiar with who we are and what we do for the MS community.

At MSAA, we are dedicated to improving lives today through vital services and compassionate support. Our services include our national toll-free helpline, an MRI access program, equipment and cooling distribution programs, educational resources, publications, digital tools, and opportunities to stay connected with other members of the community. I invite you to visit our website or to reach out to our helpline to learn more about our programs and services, and please make sure that you stay connected with MSAA. You can visit our website and sign up to receive email updates, you can follow us on social media, and you can also text MSAA to 75101 to get MS related news, updates about our programs and events, and different ways to support the MS community.

And now let's move on with some reminders and housekeeping items. During tonight's program, please make sure to submit your questions any time using the Q&A, and please know that for your convenience closed captions are available. And also, today's webinar is being recorded and will be available on our website within the next couple of weeks. And at the end of the program, please make sure to take a couple of minutes to complete the brief survey. We always welcome your suggestions, and your feedback is extremely important.

And this is just a friendly note. This program is for educational and informational purposes only and does not constitute formal recommendations. Please speak with your doctor about specific questions or concerns. And now please join me in welcoming our amazing guest speakers. First, we are honored to welcome Dr. Heidi Crayton. She is a neurologist and MS specialist. She founded the MS Center of Greater Washington in 2007 and this is the only non-academic MS center in the Mid-Atlantic region. Dr. Crayton has served as principal investigator in clinical trials of MS therapies and she has contributed to the development of treatment algorithms for MS symptoms. Dr. Crayton also serves as a member of MSAA's Health Care Advisory Council and our African American Advisory Council.

And we are also pleased to welcome Dawn Morgan. She is a nationally recognized leader in patient advocacy, women's health, and patient-centered research. Dawn has been living with multiple sclerosis for more than 20 years, and her lived experience serves as a trusted voice across research, policy, and industry. Welcome to you both. We are so excited to learn and grow together with you. Please take it away.

Dr. Heidi Crayton

Thank you. It is such a pleasure for both of us to be here. And I'm so fortunate to be able to be on this program with Dawn and for us to be able to just kind of be in our comfortable way, just talking to each other about some of these topics. Which we kind of do whenever we see each other anyway.

Dawn Morgan

Yes. Thank you so much. I am very fortunate to be here with you, Dr. Crayton, as well.

Dr. Heidi Crayton

So, Dawn and I kind of put this program together, you know, in a way that is really just kind of meant to be, like, you're just watching us kind of have a nice little conversation about some of these topics which, again, we do often times when we're together. So, there'll be slides up that have kind of our talking points and the things that we thought were important for everybody to kind of think about. But we're just going to have just some kind of shared conversation and shared discussion about some of these issues. This is a very, I think, important issue.

We know that there are ethnic differences in medicine in general, in autoimmunity, and certainly in MS. And I think that, you know, we have issues of access to health care, health care disparity, we have some things that we're going to talk about tonight, but these are truly real entities. And there are some real meaningful differences that I think are really important to kind of clarify, and to hear Dawn's perspective as well, because I think that everybody's going to leave tonight really having a better understanding of what some of these issues are.

So, the first part is, you know, understanding MS in black women and that MS looks different. And Dawn and I have talked about this a lot over the years that we've known each other. That white MS is very different than non-white MS. Black and brown MS is different. It's different. MS is different in men versus women and it's different in ethnic groups. And I think that in medicine sometimes, you know, we've kind of been so politically correct. We don't talk about ethnicity. We don't talk about, you know, sometimes weight. Some things that actually really do make an impact on how somebody actually fares in terms of their chronic condition. So I'm going to kind of ask you, Dawn, like in the very, very, very early stages of hearing MS, did you

have any kind of preconceived notion that it was something that only happened to white people, or did you feel different because you weren't a white woman?

Dawn Morgan

Yes. I was unfamiliar with the words multiple sclerosis. I may have told you a while ago, probably 20 years ago, I thought I had Parkinson's. Because the only association to neurological illnesses were Parkinson's. And I think when I was told by that particular clinician, it was a regular general practitioner at that time, she'd said, "well, it looks like MS." And I thought, okay, well, does that mean Parkinson's? Because I'd seen something across the TV that was Janet Reno, and for people who are older, they'll understand who Janet Reno was, and she had Parkinson's. And I remember when I met you, I think you had mentioned going to support groups and just finding kind of, you didn't use these words, but find your tribe was what I took from it. And so, I did. I went ahead and went to a few support groups, and I saw no one who looked like me, no one. And I thought, okay, it's just a white woman's illness with a few white men sprinkled in.

Dr. Heidi Crayton

Yeah, and I think that much of the pharmaceutical advertising, and some of the MS literature as well, really predominantly featured white people. And so, I think that that was always kind of a difficult aspect for people who weren't white. They didn't look like all the people that they saw in advertisements for MS.

Dawn Morgan

No.

Dr. Heidi Crayton

And I think that, you know, that certainly leaves out a huge part of the population. But over time, we've certainly realized that there's probably a higher risk of, you know, not being properly diagnosed because of ethnicity. That was, I think, something that was believed for a while, "well, you look, smell, taste, sound, feel like MS, but you're black so you can't be MS. What could it possibly be?" Hopefully, nobody on the line has heard something like that. I'm hoping that that's a very archaic notion. But I think that, you know, certainly gaps in representation of black and brown MS, certainly gaps in research, we don't have a whole lot of representation in terms of non-whites in the pivotal clinical trials for our MS medicines. Most of the clinical trials take place overseas, you know, in European countries. So sometimes, you know, that's a big issue. We don't really have data that tells us even how these medicines actually perform in people of color.

Dawn Morgan

Can I? Oh I'm sorry. Go ahead.

Dr. Heidi Crayton

No go ahead. Go ahead.

Dawn Morgan

Can I just say I remember having my initial symptoms and I just attributed all of those discomforts and just aches and pains to, you know, maybe going out too much, not sleeping, not being hydrated, just being overwhelmed with work, and just, you know, moving to a new city. All of those things that yeah, they possibly played a role, but it was in fact MS. And I remember going to the emergency room with a girlfriend of mine and I said, "I think I have the

flu, but I don't know what this is." And I'm just guessing, pulling straws, I don't know what made me think the flu. And, I remember saying that to the E.R. doctor, and this was a pretty reputable hospital. Everyone was very professional, and he said, "yeah, you have the flu." And I was dismissed. And at the time, I did not associate his dismissal of my symptoms, my emotional state, the fear that I may have had, I did not attribute any of that to me being black. I just thought, oh, they're rushing. They just want to get the next patient in and get me out. But later on, I found that there are some inequities here.

Dr. Heidi Crayton

Yeah. Yeah. Which is really something that's, you know, incredibly so inappropriate on so many levels. But oftentimes people who are at the highest risk for aggressive disease, end up getting delayed in terms of being diagnosed, delayed treatment... and that crucial element of ethnicity plays such a huge role in the course of your MS, that it's something that really has to be taken into consideration very, very early on if we want to have successful outcomes. Because we have lots and lots of experience and data that shows us if we don't really pay attention to the fact that somebody is not white and has MS, we're going to find ourselves behind the eight ball very quickly unless we use high efficacy medicine early on and really nip it in the bud.

So I think you're, you know, kind of proof in the pudding there. Your experience is certainly, you know, you've been an advocate for yourself though. So you did not fall into that trap. You did not result in some long, you know, delayed diagnosis and, and kind of poor care. You've always been somebody who's really advocated for equity, and you've advocated, for yourself to be heard and for your desires to be listened to. And this is one of the things I want you to kind of talk about. Maybe give people on the line who are watching some tips on really how to be seen, how to be heard, and what to look for in partnering with somebody that you want that shared partnership with.

Dawn Morgan

It starts with communication and trust. I trusted you from the start. I felt like your pattern of communication laid that groundwork. And so for me, it was-

Dr. Heidi Crayton

Discloser from Dawn. Sometimes my communication's a little wacky.

Dawn Morgan

A bit. But I think for patients and for people who are here, I think that you need to recognize number one: what kind of patient, what kind of person are you? Do you like a doctor that's more hands on and in your face and, you know, do you want someone that's a quarterback? That's going to really support you and hold your hand? Do you want someone who is more laid back and letting you take the reins? Do you want someone who's, you know, going to come in with a lot of questions for you? Do you want them to be open? You know, there's just a litany of things that you should go through as a patient and just really find out who you are and what you would like. How do you want your care? Design your care. It's really that simple.

Dr. Heidi Crayton

That's great. That's great. That's great.

Dawn Morgan

So, it's like going for a meal at a restaurant, you know, and you see a lot of things on the menu. Wonderful things. And I'm saying, because you see a lot of doctors who are highly qualified and wonderful. I have, I've not had a terrible experience. I've had some experiences that were questionable. I won't say terrible because I always try to stay positive. But I think, again, it's like going to the restaurant, looking at all of the options, and then deciding this is what I want, and piecing it together, making it work for you. Make that meal work for you so you're satisfied.

Dr. Heidi Crayton

That's a great analogy, I love that. I love that. I think that's really, you know, those are some really, really key takeaway points there because, you know, care shouldn't be one size fits all. But, I really do believe that the person that I'm interacting with should really be a partner. And there are some people, you're right, some people really do need to decide whether they want to have a health care provider who really just kind of tells them what to do, who's a little bit more dictatorial, versus somebody that they really want to partner with. I think you are completely right. You have to decide that up front. You have to decide then if you're going to trust somebody, if they've given you a reason to trust them, then you need to enter that trusting partnership. And it means, you know, two-way flow of communication. It means being open and disclosing some of your vulnerabilities and things that are important to you.

But of course, you also want to know that you're not going to be, you know, shut down. That you're not going to be dismissed. And I think that if anybody experiences anything like that, that makes them feel uncomfortable from a health care provider... you know, we're not talking about just having a fracture repaired. We're talking about a lifelong relationship for a lifelong condition. And I think that, you know, I used to joke when I would give patient talks, I'd say, you know, everybody in this audience actually spends more time shopping for a mortgage or a car loan than you do a doc. And this is a relationship you have to have, you're going to have for a while. And you need to be choosy, and you need to pick somebody that you really vibe with and that you really feel gets you and sees you as a whole person, not just a part of a person who doesn't want to, you know, piecemeal you.

Because everything that you experience in your life, certainly it's going to impact your MS. Whether you're a single parent, whether you are working and going to school, maybe having several jobs, you're navigating a bunch of different things in your life. And everybody has their stuff, you know, everybody... just everybody. We all have our stuff. And I think that that has to be recognized as part of what goes into this conversation as well.

Dawn Morgan

I think also for younger people who have MS. You may not know. Because I was never sick. I think I had a cold one or two times in my life, and then bam. You have MS. So for me, I was unaware and not sure of what I needed or what I wanted. I was in denial for probably a decade that I even had MS.

But what I love about your care is, and I feel strongly, I know for sure you set the framework. And I think it's important for others to kind of look for doctors who can set that framework, because I look for that type of care in other areas. You're not going to only see an MS specialist or a neurologist, you're going to see primary care, you're going to see a physical therapist, you may see a cardiologist and endocrinology. All of those specialists you're going to see at some point. Maybe. I don't know, but it's important to look for those things that you enjoy

in a doctor. I like your directness. I like how if I have a question, you answer. You have never been dismissive. And I know not everyone has that same, you know, wonderful flowery relationship that I'm speaking of, but I think it's on you to kind of demand that a bit. You're the patient, right?

Dr. Heidi Crayton

Right, right. You are actually a consumer of health care. So, you know, sometimes when people think of themselves in that partnership, they certainly feel like they are the one that is in the kind of the lower tier, the lower position. But you are also the consumer of health care, and you need to be a wise consumer like you would in any other aspect of your life. And you need to be prepared.

You know, there's nothing a doc hates more than anything than somebody who, I will be very honest with everybody right here and say, what we really don't want to hear is that you know more than us because that's what Google told you, or ChatGPT. Because you'll probably be dismissed. I'm just going to be honest with you. You know, when you have things to say, it's... you know, everybody wants to be respected. And you deserve to be respected. And the HCP you're working with deserves to be to be respected. And I think it's, you know, really about sharing those beliefs and just beliefs.

But it's, you know... still the foundation is trust. I have disagreements with people that I see sometimes. They bring up things that they feel very, very strongly about, and they present them as knowing more than maybe I do. And I certainly don't respond well to that. But then I'm willing to always say where my belief comes from, either from experience or from data. And I think that you have to all remember that, as well as consumers of healthcare that, you know, you might go to several neurologists and you might have several different recommendations for various things, but it's important for that HCP to be able to tell you why they're making that recommendation. Why is that the best recommendation for you? And if somebody can't answer that, then maybe that's not a great partnership for you. But I think that's what shared decision making is all about.

And that's what a shared partnership is really all about. It's about really paying attention to what my patient really wants, what they need to learn and better understand, and then to kind of go from there and talk about a shared plan of action. And if it doesn't work out so well... to have ongoing dialog about how to make that better and how to tweak the plan for success. And Dawn has always been very, very good about that as well. And I think that that's part of being a good partner is allowing the tweaking, allowing mistakes, and to say, "no, this really doesn't this doesn't work well with me. This doesn't work for me. Let's kind of do something different." So, all of those are really, you know, your responsibility.

And bringing up various times in your life in terms of your female body as well. Dawn probably has a few things to say about, you know, various stages of life. You know, there's early on when you're in family planning and then there's kind of, you know, middle life for women, and then there's menopause, which has become a big topic with MS. And I'm going to let Dawn just kind of touch on that because that's become a really, really big topic. And this is something she knows about. She has published on this topic. But this comes up quite a bit.

Dawn Morgan

So, I would like to just take one step back and just add a tip for patients also. I think in their approach to discussing different topics with their symptoms, or pain management, things like that, with their doctor or their neurologist, I think what's important is to stay away from

pseudoscience. Stay away from Doctor Google, and the worst thing you can do is go in to a doctor's appointment and say, "well, this is what I found on Google and so I believe I have this." I've done that. Well, maybe not to you, Dr. Crayton. Maybe I have. But I've used, you know, other avenues to diagnose myself. So stay away from that.

And so that leads into the menopause and MS intersection which is scary. I think the best thing that patients can do in those situations, when you have questions for your doctors and your provider, go in and approach it and say, "these are the symptoms that I am experiencing. I am afraid. I don't know what's happening, but something isn't right. Can we decide and discuss what this is together?" And I remember talking to you, I don't remember what year it was, but many years ago. And I said something is different each month when I have my regular cycle, I feel as if I'm all over the place or as if I'm having some sort of exacerbation. Well, you fast forward, all of those hormonal shifts and those changes to midlife, which is where I am now. Dr. Crayton and I met when I was a baby. I was early in my twenties.

Dr. Heidi Crayton

You're still a baby

Dawn Morgan

And now I'm in midlife. Perimenopausal age. And the symptoms do mimic a lot of what we experience in MS. Moods, mood shifting, terrible fatigue. You know, of course, the hot flashes, you know, all of the aches and pains that come with what we know to be menopausal symptoms. And I believe we have had this discussion and you did validate and said, "yes, there is a connection for sure between hormones and multiple sclerosis, and let me explain." And I think it has been a journey, trying to navigate this time with MS and this midlife transition.

Dr. Heidi Crayton

I will tell you another thing that has played out so often over my years of seeing MS patients is the burden of black women and fibroids. This is a really, really big deal. And black women are oftentimes cursed with horrendous, horrendous fibroids that not only cause discomfort, but incredibly, incredibly, heavy, heavy menstrual periods and I have women who have such incredible fatigue. You know, you can imagine when you have a cycle for 30 days and you spend a week, maybe a little bit more, losing all the blood that you've made. And you spend, well not all of it, but a lot of it, and then you spend those remaining couple of weeks of the month with your body working so hard as a factory to make all of that blood again, only to lose it.

And sometimes, you know, I have conversations with women that are really pertinent to just the black female experience, where some things need to be considered that maybe you wouldn't normally consider. Maybe you normally wouldn't consider hormonal birth control. Maybe you wouldn't consider a hysterectomy. Maybe there are things that you wouldn't consider, but I bring some of those things up to my black female patients because it so impacts their MS.

I had a woman whose walking was so horrendous. She became really disabled for two weeks of every single month because her periods were so, so out of control. She didn't have children and she was not going to have children. And we talked about whether she really needed that uterus, because a uterus has one job and only one job, it's to house a baby. And she didn't feel that she was going to use it for that. And it was really causing a lot of problems with her MS. So I had to really have multiple conversations with her gynecologist, to advocate for her to

have a hysterectomy. And when I say hysterectomy, I mean leaving ovaries there so you have a nice benefit of estrogen. But that little bag, that little muscular bag every single month was shedding a lot of blood that she worked really, really, hard to make. And I see this quite a bit. And then when I also see a woman who doesn't really, you know, get enough protein or iron, that really exacerbates that problem. It really plays a huge role in MS-related symptoms or what we feel are MS-related symptoms. So, you know, this is one particular issue which is really a big, big issue in thinking about caring for the whole black female because this comes up really, really quite a bit.

Let's just kind of segue a little bit into, you know, some of these clinical considerations that we need to think about with shaping care. We talked about higher risk for disability, higher risk for getting MS. The data tells us that the incidence of black men having MS has been pretty stable, but that there is an increasing incidence of black females being diagnosed with MS. We know that because of the location of MS spots, we have more aggressive disease. And by that we mean more involvement of the spinal cord, sometimes of the brain stem as well. And that means that even smaller spots can have bigger consequences in how you experience MS. We know that outcomes are worse, they're more involved because of that aggressive nature of MS in black and brown people, compared to white. So, it really is important to really, really, dive in quickly with really, really, good medicine to really stop this process from going on.

And I think part of that really means all of you being aware of these differences. And when I talk about this, and Dawn can maybe talk to this notion when she first even heard that there were ethnic differences with MS. I mean, even nowadays when I say that to somebody, I say, "you know, as soon as I saw what you looked like and I saw that you weren't white, my mind went off in a whole other direction of things to talk to you about in terms of treatment options versus if you were white."

So Dawn, when you were kind of entering this journey and you first saw that, you know, you were a little bit different because everything that was represented about MS was white, when were you first introduced to that notion that you should be treated differently because of ethnicity?

Dawn Morgan

I think probably. Oh, gosh. It was many, many years, almost a decade. It was maybe seven years in. I just knew something was different, but I could never... I didn't understand what was different. It was always very puzzling to me. And nothing, I shouldn't say nothing made sense, but the pieces of the puzzle were not connecting. And I remember you and I had this discussion, but it was not... it wasn't clear that I should look at MS through a different lens.

And I understood after that conversation. Completely understood that MS is not one size fits all. Particularly for people of color, black people. Although I did not have optic neuritis, which I believe is one of the... you can correct me if I'm wrong, I think that's one of the presenting symptoms for a lot of black patients initially.

Dr. Heidi Crayton

Yeah.

Dawn Morgan

But I did have a lot of mobility challenges. And so, in comparison to some of my friends, my white friends who have MS, my MS looked a little different.

Dr. Heidi Crayton

Yeah. So, tell us about navigating MS as a black woman. I think that this is your forte. How to self-advocate in the clinical setting, and navigating some of the barriers, and building a support ecosystem. I mean, these are all things that I would certainly think of you, when I thought about these ideals. So, kind of walk us through your journey in navigating and setting up your tribe and, kind of structuring that.

Dawn Morgan

I think the first step that I took was just having a moment of quiet time. Again, asking myself, "what is it that you need? How do you want to be cared for?" Care for MS. As if it's an actual person. You have to remove yourself for a moment. How are you going to care for this that is entering your space, your body, your world, every day? You will live with it for the rest of your life. So, start there. Start with yourself.

Starting to write things down. Begin journaling. I think it's really, really important to just notate, even if it's just a note on a sticky pad, "this is how I'm feeling today." Track your symptoms. That's really important because when you have your six month or nine month or twelve month, however your appointments go with your doctor, when you have your appointments, your doctor is going to ask you, "how have you been feeling? Have you had any falls?" Well, if you have to go through your memory, which we know that's sometimes called fog and is an issue with MS, it's hard for the doctor to understand where your treatment will go. So, if you don't write these things down and you don't keep a journal, it's really difficult. You can't always rely on your memory. That's pretty much what I'm saying.

It's also important to, again, the word communication. Speak up. If you're having some sort of gait trouble, talk to your doctor. Ask for a physical therapy, a script for physical therapy. Ask for... I think you and I have spoken about pelvic floor. If you're having, you know, issues with incontinence, it's really important. Go to, you know, to someone who can specialize in that area. Pelvic floor specialist, or I believe a urologist, can help guide you in that situation as well.

It's really about assembling your team. I think of that funny Dave Chappelle skit where he says... I think he's playing Prince or something, "assemble your team." You know, he tells everyone. That's really what you have to do. Have those check-ins again with yourself. And really, one of the most important pieces to this puzzle, if we're speaking about puzzles, I think finding a therapist is really, really crucial. As black women, and I'm going to be very, very, honest, we deal with a lot. Not only are we dealing with work, family... we are emotionally carrying the troubles of all of that. We are carrying losing a job. That happened to me, losing a job because you have MS. Not because of discrimination at work, but just because you cannot function because of your MS, your salary changes. Divorce. Marriage. Moving. Moving because you have MS. Moving in with family. There are so many emotional pieces that you have to deal with. Not only are we in a very tumultuous time in the world, we are carrying a lot. And it's hard. It's hard. It's hard to manage a disease and the weight of the world. That's just the truth.

Dr. Heidi Crayton

It is, and I will say that my perspective. I know that, you know, one thing that I hear often that I really don't like is not wanting help. Help is hard for all women to ask for. Men somehow don't have so much of a problem asking for help, but women have a real difficult time asking for help, and help is okay. It's okay to have others help you because it makes people feel very,

very good to be able to help you. It makes most of us feel good to help somebody else. And I oftentimes see women not allow people who care about them to help. It's also not giving in if you need something to help you function better. I call these things enabling devices, or a handicap placard. For me, it means that it gives you control over how you're going to use that finite amount of energy that you have for a day. It's not giving in. I think it's just stupid in the height of summer to park a mile away and walk to and from your car to shop because you have something to prove. That just doesn't make sense to me. So you get kind of aberrated, women get a little aberrated on help and that concept, that term.

But there are lots and lots of things that can help people actually be better, perform better, and be more in control. To treat symptoms puts you into control. If you can have your bladder urgency controlled, that gives you freedom, instead of your bladder governing your life. If you have some kind of, you know, a rollator, which is two hands on something. That means you can actually walk somewhere where there's not a wall. That gives you, you know, that opens up the whole world to you.

There are things in ways to just make life a little bit easier, and it certainly does not mean giving in. The other thing that I want to comment on is understanding. A lot of, you know, health care providers talk at a level that they really shouldn't be speaking at. It's important that you understand everything that has been discussed before you leave that appointment, and if you can't, then your HCP has not done a good job. Because communication is everything and if you leave having been communicated at, instead of communicated with, that's a fail. That was a wasted appointment. So, I think it's important to always make sure that you understand what has been communicated. Because, you know, as soon as you get home, somebody is going to ask you what went down at that appointment. And if you can't recall those things, that's no good.

You can take notes. That's perfectly fine. But you need to be in control of what's best for you and how best your health care team can be of service to you. And only you can really do that. So, Dawn and I both are really strong advocates of being an advocate for yourself. And the HCP side has to do a better job of really recognizing some of those cultural differences, some of the environmental differences, some of the social differences, and just being there for you and just acknowledging those things. We can't always fix them, but just to be there to acknowledge those things.

So, next segue is into kind of turning knowledge into power and action, and nobody does this better than Dawn. She's really been such an advocate for herself and for others. But really, you know, she's been giving you here lots of tidbits and different tools to put in your toolkit.

But some of the things that are listed here are really important. She was just talking about tracking symptoms and treatment responses. That's a huge one. I'm a big manager of MS symptoms, and if people aren't aware of their symptoms, when their symptoms bother them, or if they want them treated, then they can't really give me guidance on whether or not I'm doing a good job treating those things. So, understanding your MS is really important. Not what you've read about, but your MS. And medications. You need to, you know, you need to ask questions. I don't get very excited about a patient who rattles off medicines, but they don't really know what they're for. They're just taking things because they were just given to them. They don't know if they work. That's not really being empowered.

To talk about some of these other things Dawn, like, you know, boundaries, and strength, and the changing definition of those concepts actually.

Dawn Morgan

Boundaries with your health care provider or?

Dr. Heidi Crayton

Or everybody else, or work, or your loved ones.

Dawn Morgan

You said something to me many years ago, and you've repeated it. You probably don't remember, but I remember telling you, again I'm thinking I'm superwoman, that I can do everything in one day, and you said, "why, what are you doing? What does your day look like?" And I said, well, I have to do this, I do that, I'm doing that, you know, and I gave you this laundry list of everything that I had done. And I did not set boundaries. I had not set boundaries.

Dr. Heidi Crayton

I think I probably jumped in there and said I thought you were crazy.

Dawn Morgan

I think you did

Dr. Heidi Crayton

Which as an HCP you probably shouldn't do, but I think I did.

Dawn Morgan

I think you did. But it was such a wake up call. And again, that speaks to the relationship that we've cultivated. That I am able to acknowledge, yeah, you're being a little nutty, and yeah, you do need to listen to your doctor. You don't know everything because I am that patient. Sorry, folks. I'm that patient who thinks she knows everything. And I'm very...

Dr. Heidi Crayton

She is.

Dawn Morgan

Probably why I have a son who thinks he knows everything, too. But I had to tell, you know, my job, "I need accommodations. Yeah, you've placed these items on my checklist of daily duties, but I can no longer do that. I've given you my paperwork stating that I have MS, that I do need accommodations. So here are the boundaries, and I'm not going to give in. Because I'm tired, not because I haven't slept, because I did. I had ten hours of sleep. I'm tired because MS is really kicking me in the rear or I'm tired because my hormones are fluctuating and I don't know what to do."

There's a combination here. I think it's really important to just, like Dr. Crayton told me, do one thing. Choose something that you can do in that day. If you have to go to Costco and you have a doctor's appointment, you know what? A doctor's appointment is important. Costco will be there. They will be there smiling and ready to check your card when you walk in tomorrow. So those are things that you have to look at. And it's just really important.

Don't park a mile away and walk. Get over the vanity of putting the handicapped placard. Who cares? Okay, people look at me all the time and say, and I've had very rude people say, "well,

you don't look like you have anything wrong with you, why are you parking there?" Well, it's none of your business. Sorry, I'm going to use my placard. You know, there are days where I want to have a little bit of exercise, so I might park, you know, a few spaces down. But I'm going to utilize what I have because the preservation of energy is more important. Making dinner for myself, for my family, that is more important. Having the energy to do homework with my son, that is more important than looking cute, walking a mile away, and not using that handicap placard. Or telling your job at work "I appreciate that you trust me with all of this work. However, I can only do this task today and my productivity will be so much better if I'm only allowed to do this." Set the parameters for yourself.

Dr. Heidi Crayton

Exactly, exactly. I think one of the most difficult things about MS I hear from a lot of people, is the unpredictability, the lack of control. And when you are an advocate for yourself, you set boundaries, you ask for what you want, you play an active role in your health, that is empowering. I view that as empowering, and I view that as a very empowered partner that I'm working with.

So, I don't view those things as giving in. I view those things as people taking their control back. And I think that's a really important part of MS. Sometimes it takes a little while to regain that control and know what that looks like. This is kind of a... I like this slide here about, you know, clinical language and assumptions and, you know, things that can be missed.

Sometimes there's a mismatch between lived experience and, you know, what you're being told when the doc says "oh, your MRI is fine, you know, there's no relapses so everything is just fine and dandy and your disease is under control." And you feel like garbage, and you feel like you're changing, you feel like your symptoms are getting worse, and those sorts of times are when you need to be a voice for yourself. You need to be an advocate. You need to speak up. You need to be validated, seen, and heard. And, you know, I like people to use language that I can understand. I ask people, "what would you do to me to make me feel the way that you feel?" So, it's important for you to be able to communicate those things and expectations. And if you want more, you need to express that. I'm sure you have something to add to that, Dawn.

Dawn Morgan

No. And that just brings tears to my eyes because you don't have... many doctors don't have that care. And you have to have that great bedside manner in order to get patients to open up in that way I think, sometimes. Especially if you see a patient that's a little bit reluctant to share, you know, what's happening. So, you saying, tell me how I think you... I'm sorry, brain fog again.

Dr. Heidi Crayton

Yeah, yeah. What would you do to me to make me feel that way? Because sometimes it's really hard to put into words.

Dawn Morgan

Right

Dr. Heidi Crayton

Sometimes there are no adjectives for what you all feel.

Dawn Morgan

Right.

Dr. Heidi Crayton

There are just weird things.

Dawn Morgan

I remember telling my dad, because no one understood in my family what was happening, and I was telling him, "imagine buttoning a shirt," and I got this from the MS society I believe, but I literally felt this way, "imagine getting like construction gloves and then putting on ski gloves, like two pair of gloves, and try to button your shirt." That's how it feels. It's impossible.

Dr. Heidi Crayton

Yeah, those things are important.

Dawn Morgan

I have a question for you. I guess it goes along with these slides. When you don't see, I suppose, some sort of enhanced lesion on an MRI. But the patient feels, and you do see progression. What is happening? That's always been a question that I've had in my mind.

Dr. Heidi Crayton

Yeah. Sometimes it's a, you know, the hard part is that everybody with MS is different day to day and you're all different within the same day. You're different person at the end of the day than you are at the beginning of the day. And you're different today than you were yesterday, or you're going to be tomorrow. Because there's so many factors. Change of season, change of temperature, change of barometric pressure, stress in one's life, affects how your MS plays out.

There's so many different ups and downs. And then you know, your monthly menstrual cycle and so much going on that I try to convey the fact that I'm, you know, when you're going to your physician, your appointment, every six months or whatever, that's really the bird's eye overall objective view. Despite the fact that you have a lot of lumpy bumpiness. And so sometimes people think living in that body with a lot of ups and downs, that it's really a decline. Sometimes it's not. Sometimes that objective exam is able to say, no, you're exactly the same, but we need to we need to give you more tools in your toolkit to manage some of that wavering that you experience because of outside influences.

Then we do have people that do go on to kind of have slow, steady change despite being on really good medicine. And we can switch around to different medicines and try different things. And that's what happens most of the time. But it has to be something that, you know, oftentimes you're bringing to the medical community. You know, I'm not doing as well as I had expected to be doing, and that needs to be that needs to be shaped.

So, I think just, you know, a couple of key takeaways here from tonight. You know, some things to really, really, think about. And I think first and foremost is to advocate for yourself. To really trust your voice. To insist that you're seen and you're heard. And really, only you can make that happen. And if you know you're with a health care provider or a health care team that doesn't automatically deliver that to you, feel free to try to train them and to try to maybe show them how to do a better job of becoming what you want. Everybody can change. Everybody can learn.

I think it's important to, you know, share your experiences. You know, to support other women. I think, you know, in my practice, I try to match people who look alike. I like to match or pair up, you know, young black women or men, or young black, you know, people of like, ethnicity and of sort of same age range. Of what they're, you know, going through in life. If it's somebody who's Hispanic, if it's somebody who's Middle Eastern, I just try to. Because I think that there's some of those cultural differences and ethnic differences are really, really, important in how this plays out and how you deal with MS. So, I think it's really important to have a peer that has something more in common with you than just MS.

Staying connected. You know, your community. And I think the MSAA... this is a prime example of the wonderful work that they do. This is one of the few organizations that I'm aware of that really does focus in on ethnicity as a topic. And it is a really, really important, real topic. And I think that, you know, with the turnout from tonight and, you know... I think all of us here tonight, including Dawn and I, are very, very passionate about this topic. And that it's all about honoring black and brown women, their voices, their concerns, and empowerment and empowering each other to be as successful as possible with this unpredictable pain in the butt condition.

So here's some good resources, and I think I'm going to leave that up. Nice to have some resources to follow and get other information from. And I'm going to leave that one up while we maybe take some questions. Dawn and I are open for some questions in our last five minutes or so.

Dawn Morgan

Can I just say one thing before we get to the questions? I want to say thank you to you, Dr. Crayton, because I don't think you get enough of that. A lot of times patients will come in with, "oh, this is what's happening." And they forget to ask you, "how are you doing? How's your day?" Because you don't get enough praise. And I have to say thank you. With that being said, you gave me my life back and MSAA gave me a part of my life back as well.

Many years ago, I think I mentioned how I had this fatigue and heat intolerance, and I was just miserable. And I did not understand why I couldn't go out to an outdoor concert in the summer because I was miserable. And you said "Call MSAA, and you will be able to get a cooling vest." And you all sent me one and it changed my life. And I thank you for that. So both of you.

Dr. Heidi Crayton

They do great work. Thank you. Thank you honey.

Yahaira Rivera

Thank you both for your honesty, your insight, and this amazing conversation. We appreciate the way you shared both the professional expertise and the real experiences of black women living with MS. And Dawn, thank you so much for that feedback and that testimony. We're glad to hear that MSAA has been part of your journey.

And we have amazing questions. So I'm trying to summarize them, because they're important. And if you don't mind... staying with me a little longer so that we can address some of those important questions. Some of them are around, not everyone is lucky or blessed enough to live nearby an MS specialist or MS center. We have community members living in rural

communities, and they don't have easy access to providers who are knowledgeable in MS. What is your advice for these community members?

Dr. Heidi Crayton

That is... I think that's probably the majority of people, don't have access to somebody who is a full time MS specialist. I think being part of various educational online webinars is really important so that you can see and hear and understand what some of the viewpoints are of people who are MS specialists. I think that's really, really important. I think it is important to make the effort every once in a while to just... to go to somebody that you've seen or heard about that you think that you might value an opinion from. Even if it's a one-time... just to kind of get a consultation to make sure that you're on the right path.

Sometimes it's worthwhile traveling an hour or two hours for a once-a-year visit. And then you can have your day-to-day care much closer to home. But I think it's important that you not feel that you're stuck with inadequate care, or a care partnership that you're not really fond of. You have to find somebody you can communicate with and partner with. You're worth it.

Dawn Morgan

You are. I think also just one piece from a patient perspective, I think if you utilize... number one, the resources here. You know, tap into these areas because there are plenty of people that can provide information for you. But also look up your local... your closest medical center. Your university. You know, universities usually have some sort of medical center or some sort of attachment. So, people can point you in the right directions. Again, ask. Just ask.

Dr. Heidi Crayton

Yeah, yeah.

Yahaira Rivera

Thank you both for your advice. Our next question. "I have encountered many practitioners who do not want to answer my questions. They react as if my curiosity is about challenging their authority. They react by condescending yelling, screaming, or dismissing me."

Dr. Heidi Crayton

Oh my gosh.

Yahaira Rivera

So the question is, "where can I find good care and what will be the next step?"

Dr. Heidi Crayton

That's a hard one. I do hear that people experienced interactions like that, and it's frankly embarrassing. And I give a very broad apology on behalf of the neurology community when I hear something like that. I think that it's really a matter of shopping around. You know, there are a lot of different people that have an online presence. You know, maybe you have other outlets where you can get your questions answered by other docs that you really enjoy through online programs and things like that, and you just utilize, again, you're in the driver's seat, you just utilize that one person that you interact with for basic, basic level care, but you're getting a lot of input from other people that you, you know, participate in programs with.

Sometimes it really is worthwhile to just be honest and just say, "you know what? I'm the one who's living with this, not you. And I just have some concerns, and I just want to better

understand this." You know, sometimes just making yourself vulnerable really breaks down some, you know, that barrier. If it doesn't, then maybe that's really, really not the provider for you. They have to be respectful of your feelings and of your choices and desires.

Yahaira Rivera

Thank you so much, Dr. Crayton. Our next question is, "I was recently told by a social program that in order to qualify, I need to come in so that they can see my disability. I don't use a wheelchair or anything like that. So how will they see my MS?"

Dr. Heidi Crayton

I assume maybe that meant like for, or maybe for... disability, or Social Security disability, things like that. And when you have invisible MS... which frankly, I think is sometimes the hardest MS to have... it's really, really difficult because we are a very ignorant society, and if we don't see you dragging your leg, using a cane, or something like that, we think that you must be just fine. And in those kinds of situations, it really takes a strong doctor's note. It really takes good medical records to be able to document and that's why it's important at those interactions, you have to really not hold back and throw out all the symptoms and barriers to a high functioning life that you experience because of MS.

You need to talk about all the fatigue. You need to talk about the cognitive dysfunction that you have. You need to talk about the depression. You need to talk about the bladder urgency. All those things that nobody ever wants to talk about because they're embarrassing, they're things you try to put behind, you don't want to talk about them, but those are the things that are really, that make invisible MS very, very difficult.

And those things need to be validated and documented in the case where somebody's legs are okay, but they have invisible MS. They sometimes even have sensation differences. I had a patient who felt like she was being burned by a branding iron all the time. That's pretty disabling. You know, those things need to be well documented because they're not visible. So, there's nothing that you can do without that documentation. So, it behooves you to have those frank discussions with your health care team.

Yahaira Rivera

Thank you so much Dr. Crayton. We have a community member, and she's sharing her experience with us, and asking about the new high efficacy drugs and the side effects. She was recently diagnosed with MS, but also with breast cancer.

Dr. Heidi Crayton

So oftentimes what we do in that situation when somebody is going to be treated for cancer with chemotherapy, for instance, is forgo the MS treatment and let the chemotherapy treat the MS as well. Before we had any of the disease modifying agents that we have on the market. Before we had those things, we oftentimes used chemotherapeutic medicines to treat MS. Because they are, in essence, oftentimes kind of blanket immunosuppressant sorts of medicines to just kind of beat down the immune system.

So it means you don't want to double dip. You don't necessarily want to have somebody on an MS medicine in addition to a cancer chemotherapy drug. So, oftentimes I will take people off or not even start an MS medicine, and maybe just treat some of their MS symptoms with symptom medicines, but allow the chemotherapy to treat the MS as well.

Yahaira Rivera

Thank you so much. And we have another question. It reads, "I have been diagnosed since 2001 and I have slowly progressed. When I turned 62, my neurologist said that the DMT no longer works on older people. Is this true?"

Dr. Heidi Crayton

So there's a lot of controversy to that statement. There was a study that came out of Johns Hopkins looking at whether or not people needed to be treated after the age of, well, they called it 55. And whether taking people off of medicines was appropriate. Because as we all age, with or without MS, as we all age, our immune systems all start to decline. That's why people oftentimes in their 70s and 80s have more coughs and colds and flu sorts of things. When we have people who have autoimmune disorders like MS which is too much immune system response, those things are going to quiet down with age.

So the thought is, maybe people don't need these heavy duty MS drugs after the age of 60. So, sometimes that works out, sometimes it doesn't work out. I don't think it's appropriate to blanketly take everybody off of medicines. I think that it's really a case by case decision and if the decision is made between the patient and the doc to stop an MS medicine, it doesn't mean let me know if something bad happens. It means annual MRI's and keeping an eye on that person to make sure that nothing happens. But no, it is not a general rule across the board that everybody says, "yeah, once you're 60, come off of medicines." No.

Yahaira Rivera

Thank you for that. And before we conclude our program, I would like to ask both of you if you have a final takeaway or piece of advice to everyone who's listening to you both tonight.

Dr. Heidi Crayton

Dawn, why don't you go first?

Dawn Morgan

Piece of advice. Two words come to mind. Be curious. Curiosity is something that can be very, very helpful while navigating your MS journey. And I believe it can lead you in the right direction. And I say that because it leads you to the right doctors, the right care. And just knowing your body, knowing your MS, you have to really know what's happening. You can't ignore it. It's going to be there. So be curious and don't be fearful.

And the last thing I'll say is, it's okay. Dr. Crayton mentioned vulnerability. It's okay to be vulnerable. Know that you're not alone and there is support, a tremendous amount of support, in this community. And all you have to do is reach out. There are so many people that will sit on the phone, or emails and text messages, for hours and just talk about MS with you if that's what you want. So, be curious and be vulnerable.

Dr. Heidi Crayton

Love that. Gosh, kind of hard to top. I concur and really choosing your support I think is really, really important.

It can be, you know, it can be blood family, it can be close friends who are family, it can be, you know, people that you find through support groups. I think it's important for you to have at least one person that you know who has MS. Who knows what it's like to wake up and feel MS.

People love you, they support you, but unless you have MS, you have no idea what that statement means. And I think that's really important. And it's important to be seen and be heard in a way that you feel validated. And that just kind of recumbent on all of you to make that happen.

Yahaira Rivera

Thank you so much to both of you. Once again we are so grateful for this crucial conversation, your honesty, your candid advice, and insights, and for amplifying the voices of black and brown women living with multiple sclerosis. We appreciate you both so much. And thank you to our wonderful audience. We received so many comments. Everyone is engaged in conversation, sharing about their experiences, so we see you and we hear you. So, thank you so much for being part of our community. And just a quick reminder that this webinar was recorded. So you'll get to watch it again and share with family and friends once it's available on our website. And please take a few minutes to complete the survey.

Your feedback is so important to us, and it helps us to develop future programs and content. And on behalf of everyone here at MSAA, thank you for participating. We hope that you leave this webinar feeling empowered and supported. MSAA is here to be part of your journey. Have a great evening and Happy Black History Month! Thank you Dr. Crayton and thank you Dawn. Bye bye.