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Multiple Sclerosis Association of America

# Our Voices: Celebrating Black History Month and Black MS Patients

Presented by:

Heidi Crayton, MD

**Darion Banister:**
Well hello, everyone. Good evening and Happy Black History Month. It is now 8 p.m. on the dot. As a few folks are still coming in we're going to go ahead and get started, and we'd like to welcome you to our webinar tonight, Our Voices: Celebrating Black History Month and Black MS Patients, those that are living with MS and those that are thriving, doing well and living well and living fully. We are here to celebrate you all and we want to thank you all for joining us tonight. I am Darion Banister. I am the new, well, I guess not so new anymore, Director of Health Education and Equity here at MSAA and I am proud to be here to join you all and welcoming our amazing presenter. But first, we just have a few housekeeping rules and a few things to share with you all.

First of all, who are we? We are the Multiple Sclerosis Association of America and we are the leading resource for the entire MS community, improving lives today through vital services and support. We have many services that we love to offer and we have a helpline that exactly is right here. Please remember this number, (800) 532-7667. Extension 154. And of course everything is also available in Spanish. And we have great news to share with you all. Our MRI program is back and it's fully working. We are here to support you all with MRI access. Please make sure you give us a call at this number down here and the extension. And please make sure you visit MSAA to learn about all of the amazing programs that we have coming up. And we may be in a city near you very soon.

A few reminders for tonight. Remember during tonight's program, feel free to submit all of your questions using the Q&A feature at the Zoom bar at the bottom. And then, of course, you know, today's webinar will be recorded and available as on demand for your viewing pleasure in a couple of weeks after we finish. And please don't forget, it's very important to remember the brief survey at the end for your feedback. It is extremely important. Your feedback shares with us how we move forward with our programs. It shares information for research purposes and how we can make sure we're bringing better programs to you, both virtual and in-person.

And without further ado. Oh, I almost forgot our disclaimer. Can't forget that. As a friendly reminder, this program is for informational and educational purposes only and does not constitute formal recommendations. Have to let you know. Please speak with your primary doctor or healthcare provider for specific questions or concerns about your diagnosis and treatment.

Now, one of the best parts of the day. The best thing I can do today is introduce our phenomenal, world renowned speaker. She's a speaker. She's also a neurologist by trade. But let me tell you, she's going to be fabulous tonight. The wonderful, the beautiful Dr. Heidi Crayton. She's a board certified neurologist with the specialty in multiple sclerosis. She grew up in the Los Angeles area, but came east to attend medical school at the Medical College of Pennsylvania, and after that she pursued a residency in adult neurology at Georgetown University Hospital. She subsequently did a fellowship in multiple sclerosis at Georgetown under the mentorship of the legend Dr. John Richard, and went on to establish a full time MS center in Georgetown. So if you're in the area, look her up.

She left Georgetown and established the MS Center of Greater Washington in 2007, the only full time nonacademic MS center in the mid-Atlantic region. That is phenomenal. She focuses on patient care in addition to involvement in the clinical research. She has been the principal investigator in clinical trials for MS therapeutics, and has been involved with developing a treatment algorithm for symptom management in MS. She lectures to patients as well as physicians nationwide and globally as a part of her mission to educate and improve the lives of those living with MS. You know, I can't say anything else, but I also want to say she's also a member of MSAA's Healthcare Advisory Council and our African-American Advisory Board. Now, please welcome, join me in welcoming the phenomenal Dr. Heidi Crayton. Dr. Crayton, please take it away.

**Dr. Heidi Crayton:**
It is a pleasure to be here. It's really, really, a pleasure to be here with you all tonight and to celebrate Black History Month. And we're getting close to Valentine's, so I'm in red tonight. I hope this is an educational event for you. And I hope to have you leave with a little bit more information than you came this evening with. I think that everybody, even if you had MS for a really long time, I hope that you can gain a little bit and learn a little bit of something that you didn't know before you entered the party tonight. So I'm gonna start off by just kind of doing a little brief MS 101. I like to do that whenever I'm speaking, just because everybody needs to be on the same page. Sometimes people have beliefs that they've had for a long, long time that really aren't valid. So just to kind of make sure that we're all... we all have the same understanding of MS and what MS is and what MS is not.

So, to make a diagnosis of MS somebody has to have signs and symptoms there's something going on within the central nervous system. The central nervous system means any part of the brain, any part of the spinal cord. There are only two requirements for a diagnosis of MS, and they are the same two things that have been used historically for hundreds of years, because MS has been talked about for hundreds of years. It's been written about books. Pictures have been drawn of people with MS. It's been around for a long time in white people. But the two key elements are having something funky happen in the central nervous system, separated in time and space. What that means is, the space part means, different parts of the central nervous system, like the brain and something in the spinal cord or something in your optic nerve and your spinal cord. So different areas within the central nervous system. And having things happen at different times. So it can't be just one run on episode of symptom weirdness. It has to be that something happened, maybe involving your vision, and then at some later time down the road, you had something happen with your legs. So a different part of the nervous system happening at a different time point.

And then we do all kinds of testing to make sure that we rule out things that are not the case, and that we have evidence for MS. Imaging, we use MRIs. MRIs came around in the late 80s. Before that, MS was a difficult diagnosis to make. Sometimes what they would do is put people in a hot tub and see if they could get out, because so many people become very symptomatic and become very weak when they overheat. So that was oftentimes the diagnostic test, was putting people in a hot tub and seeing if they could get out. Now, not so cruel and unusual. Now, some people would say an MRI is cruel and unusual, but, some people fall asleep. Some people get a little anxious before an MRI. But MRI is really the easiest way for us to diagnose. We can see spots that are really essentially little scars in the nervous system, either happening on the brain or within the spinal cord. Spinal taps are done some times, and that's to see if there's evidence of your immune system being kind of revved up within your nervous system. We don't do that as often. I haven't done a spinal tap in ages because we have MRI scans.

And this is just an image of what we're looking for when we're looking at the MRI. We're looking for spots that that show up as white spots. We're looking for where they're located, how big they are. And then when they give you the IV contrast, we want to know if they light up or not, because if they light up, that means there's active inflammation. And if things do light up when you have the by contrast, they do that for about 30 days or so, if something doesn't light up with the IV contrast, we know it's at least 30 days old, maybe a little bit longer. So that kind of tells us what's going on.

Everybody's MS is totally, totally different. And your symptoms are 100% dependent on where you have those scars located. It's location, location, location. It's just like real estate. So people have many, many, many different symptoms. And even when people say they have the same symptom, they exhibit it or express that totally different than the next person. But whether you have spots in your brain or your spinal cord definitely determines what kind of symptoms you have from your MS. People can have a lot of spots in their brain and really not even be aware that they have much going on, or that there's anything wrong. They can have one spot in the spinal cord and they definitely know something's wrong. I kind of think about it, because I'm from Los Angeles, I think about six lane highways. And if a car breaks down on a six lane highway, other cars can kind of go around it. And that's kind of how your brain is. So if you have a spot somewhere, there's a little glitch in the in the pathway, pathways can just go around if you have a little MS scar in your spinal cord, everything that starts in your brain has to go down through that glitchy area, and all sensation from your feet have to come all the way up to get to your brain, to that glitchy area. So all it takes is one spot. And I think about that as a car breaking down in a tunnel, you get backed up. So, anything can can kind of be affected, and wherever the issue occurs for that little glitchy ness in the nervous system determines how you express MS and what symptoms you have from your MS.

So, people always want to know what kind of MS they have. And I don't really like that question. It's my least favorite question that people ask. We have these artificial categories, and I'm going to just kind of illustrate them for you just so you understand what's meant by those terms. But the categories kind of have pros and cons. You know, to pigeonhole somebody in a particular category when we may not have a medicine for that category, then kind of puts us in a predicament because then it maybe inhibits prescribing of MS medications for you because you've been pigeonholed. So I don't ever, ever, ever put the type of MS that somebody has in my notes, in my chart on a patient. I just say they have MS and they're either doing well on a medicine or they're not doing well. And if I want to switch to a different medicine, that's all Big Brother needs to know. I don't feel like there's ever any need, except for clinical trials and clinical research, where we're really looking for different types and categories of MS, that's the only time I ever really think about it. We really do use those for clinical trials.

So the most common type of MS and the the type of MS most people have when they're diagnosed is relapsing-remitting MS. And this can be a little confusing for people because the word remission, we think about cancer, and when somebody is in remission that means they have no cancer. And people are never without MS. So I think sometimes that term is confusing for people because if you have ongoing symptoms, you might think you have progression in your MS or you have progressive MS, because you're always aware of the fact that you have MS, you always have some symptoms. And that's not the case. What relapsing-remitting MS means is that you have some episode, some symptom happened to you, and then you have some recovery. You have either 100% recovery or maybe you don't get all the way better, but you're stable in between attacks. So somebody can say, Yes, last week, last Monday I woke up and my right arm was numb and tingly, versus being able to say, Well, I'm not really sure when the symptoms started. So very, very defined time period when it starts and and when it quiets down. Again, you might get 100% better. You might not get 100% better. I have some people that had optic neuritis at some point in their life. They went completely blind. Some people got 100% better. Some people say, oh, I'm mostly better, but I'm I'm not 20/20. I never, ever, ever went back to 100% normal. But as this little graph illustrates, even in complete recovery, with quiet, stableness in between attacks, that's relapsing-remitting MS.

As opposed to secondary-progressive MS, where people start off having relapses, they have relapses and quieting down, but then they go on to just have kind of slow, steady change. They can't say that something happened last Monday. They can just say, I'm different than I was six months ago. I'm going to be, you know, shopping at the holidays really more online because I really can't, I don't have the strength, the stamina to go out shopping. So really unclear exactly when that happened. When that change happened. But people know that they're different than they were 3 or 6 months ago. So secondary progressive MS, they started off with having defined relapses, but then kind of went on to have this slow, steady change. And people who have [secondary-progressive MS], they say they have never, ever had a relapse. They've never ever known something to happen and and have a period of stability. Things just kind of kept happening and kept happening and kept happening and building on each other. So those are, kind of, the differentiating factors, if you will, between the categories of MS. But again, my personal feeling is that they're really arbitrary. And I think of MS on a spectrum and people fall someplace along that spectrum. I don't like personally to pigeonhole people into these categories because I like to have, I have a whole bunch of medicines in my toolbox, and I like to be able to choose what we're going to discuss as a treatment option.

So MS has traditionally been thought of as something that white people experience. For a long, long time, anybody that was nonwhite, black, Hispanic, Middle Eastern, were told that even if they had symptoms that kind of look, smell, taste, and felt like MS that it probably wasn't, because they weren't white. And MS, I told you, has been around for hundreds of years. Well it's been around for a long, long time, but really, in relation to white folks; to people, mostly, European populations. And then here in the United States, there are clusters, higher incidence, further away we get from the equator, especially up in the the northeast, the upper states within the United States, have really quite a bit of MS, when you look at kind of geographical differences here within the US.

And we see that within other continents as well. There are studies like in Australia. And again, the further away from the equator, there's a higher incidence of MS. We're not quite sure what that's all about, whether it has to do with vitamin D exposure or lack thereof for people who live the farther away from the equator. We do know that vitamin D deficiency does play a role. And most people, I think, are vitamin D deficient. Really, really white people are deficient because they have very sensitive skin, and they've been told to protect themselves when they go into the sun. We should all, to a certain extent, be protecting our skin when we go into the sun. Darker skin has even less ability to absorb vitamin D from the sun, though, so my black folks are as vitamin D deficient as my really white people who don't go in the sun. So vitamin D is most efficient from the sun, but that comes with other risks. So at the very least, once you have a diagnosis of MS, we certainly want to make sure that you're taking adequate amounts of vitamin D to keep your levels adequate. And when you get your your blood test done, normal is between 30 and 100. And for MS, we like that level to be at least 50.

So, let's kind of talk about the fact that for a long time, MS was really thought of as just something that happened to white folks, that there was no such thing as black MS. Well, we know that that's not the case. We know that there is black MS, there's Hispanic MS, there's Middle Eastern heritage that experiences MS, as well. And it's very, very different. And, this is really the time when medicine really has to come to grips with some differences that we have to really, really look at because we have to treat people appropriately and stop being so politically correct sometimes and not look at weight, not look at ethnicity, because some of these factors about an individual really do dictate how a different condition is going to manifest itself. And with the case of MS, and really most autoimmune conditions, non-whites have more severe manifestations of those conditions, including MS. So, people... I treat non-white MS very, very differently than I treat black or brown MS.

Overall, there's an increasing incidence of black females being diagnosed with MS. The incidence of black men with MS has really been pretty stable. We're not quite sure what this is all about or why this is, if it's a matter of awareness, or if it's really a matter of really increasing incidence, or whatever factors there are. We also know that MS in blacks tends to be a lot more involved. And by involved I mean more spinal cord involvement and more optic nerve involvement. We don't like spinal cord involvement because that's what results in people certainly being aware of having MS. That's what results in people having problems with walking with balance, with their legs in general, or with their arms, with their bladder, bowels, erectile dysfunction, things that you really are aware of. And so we think of that as being a little bit more aggressive MS, and we don't like it. And that's what we tend to see more often in non-white MS.

There's certainly a need for early intervention. And it's really, really important to treat highly, highly effective right out of the gate. And I've been doing MS for 30 years. I really can't imagine doing anything else other than MS. And I have learned over time that non-white MS has to be treated incredibly aggressively right out of the gate. Otherwise, we find ourselves behind the eight ball very, very quickly. And over the years, I've really tried to impart this notion to neurologists. And I'll let you into a really, really big secret - Neurologists are typically pretty conservative people. Neurologists are typically not dealing with conditions where you have to really dive in and make a difference. We haven't even had a lot of tools over the decades to treat a lot of neurological conditions, especially something like MS. And MS, for a long time, was diagnosed “not eos.” It meant that we just kind of patted people on the back and said, well, I can give you some steroids if you have a relapse.

But other than that, there's nothing that we can do for you. It really wasn't until the 90s that we even started to have medicines for MS. and the medicines that came out, initially, they were okay, they were better than nothing, but we also know that black MS really didn't respond very well to those initial injectable medicines that came out; they didn't really do a whole lot for non-white MS. Whites responded much, much better to those medicines. And as we've had further expansion of various medicines to be able to use, we have pills, we have IV medicines. But we really need to treat to your level of MS, to your degree of MS. and everybody really is again, so different. But I err on the side of being maybe overly aggressive in my treatment, because if I have anybody who is black or brown, I really toss out many, many options. And I really focus on some higher efficacy medicines from the outset, because there's just... time is important and we just don't really have the time to waste. And we really want to make sure that we dive in there and make a difference.

And when I talk about this with docs, sometimes, I can talk about the fact that, like, with cancer, somebody who has stage three cancer, stage four cancer, we don't start with medicines that are less effective - less side effect, they're super, super safe, and they were “kind of sorta.” We don't do that. We know that somebody really needs to be treated with gusto, and we give them the best there is. And we say this is how we're going to manage side effects, this is how we're going to manage risks. But it's really important that we really, really pull back on the reins here of this disease that you have. And that's how we need to treat MS, as well. We really can't just kind of dance around in the beginning and hope that somebody who, by definition, being black or brown, that they're going to be okay, unless we really, really make a difference. And we make that difference early on in the MS disease course.

The other thing that's really important, I think is really important, it is my my passion project, it's near and dear to my heart, is symptom management. And I think that we have not really done a great job over the decades really helping people navigate symptoms of MS. I know that everybody's very concerned, and there's a lot of importance placed on the medicine for MS, and the medicine is going to have the most effect at decreasing the chances of new things occurring, but I think for patients living with MS, what you really, really, really care about the most is yes, that your MS is controlled, but gosh, you have got to have symptoms managed so you can live your life as fully as possible, as comfortably as possible.

And I always say to my patients, I really want you to put your MS in the back seat. It is not the driver of your life. It needs to be in the back seat. And people say, how can I when I feel like garbage? My MS definitely runs the show. My bladder runs the show. My fatigue runs the show. My stiffness runs the show. All of these various symptoms are what impact me day to day, and how successful I can live with MS. And there's a lot that can be done about symptoms. Sometimes you want something really, really, really quick. Sometimes that's very difficult to do. If you're willing to be patient, there's a lot of kind of trial and error and trying to find the best fit for you. I try to teach people how to treat their symptoms, what medicines we use for a particular symptom, and then we kind of tweak to your individual symptoms. Because, I might treat someone's bladder issue one way, the next patient I see, I'm going to do something totally, totally different that helps with the story that they give me. So symptom management is really important as well.

So when I see somebody who's not white, I always image the spinal cord because I'm almost always, always, I'm hard pressed to say that I've never, ever, ever seen anything in the spinal cord when I thought something was there. So it's important to make sure that your spinal cord is looked at. And if you have something in your spinal cord, that kind of ups the ante in terms of your requirement for really good medicine, for really efficient, highly effective medicine. And, you need to have your symptoms managed so that you can live successfully with MS.

So sometimes the issue is a matter of delayed diagnosis. And maybe not everybody has a diagnosis early on in their disease course. You know, sometimes black MS is delayed, that diagnosis is delayed because there's lack of recognition that blacks can get MS. I mean, I've heard that story a lot. Well, you know, kind of seems like it could be MS, but black people don't really get MS. I'm hoping that that's something of the past. I really am hoping that I never, ever,

ever see a patient again who says that, who tells me that story. But I hear some kind of crazy stories sometimes, still, in this day and age. But certainly that's something out there. Some people, you know, don't think that MS can happen to black and brown people. Access to healthcare might be another issue, for sure. Maybe being able to get into a neurologist, a specialist, sometimes that's a matter of geography, sometimes it's socioeconomic, sometimes it's geography - where you live and what kind of access to healthcare you might have.

Sometimes it can be a little bit more silent in terms of what happens early on in your MS, especially if people have a lot that happens in the brain initially. If it's not in a really important pathway, you might not even be aware of it. I see people sometimes that are diagnosed, that are newly diagnosed, or I'm confirming the fact that they have MS, and they... to them, they're brand spanking new, they're newly diagnosed. I can see on their brain MRI though, that they have a lot of lesions and that they have a lot of really, really, really, really old scars, that they've had it for a really long time. Those spots were never in a place that made themselves aware. So sometimes that can happen as well, that you can have involvement in areas that are kind of silent.

And then we have cultural issues. We have cultural issues with the American healthcare system, rightfully so. The American healthcare system, the United States government has not always been fair, has not always played fair, and not presented medicine in a very fair manner. Historically, there's been a lot of distrust, and some of that is cultural. You know, we see that in Hispanic populations, we see black populations, we see Middle Eastern populations. There are cultural differences and people have to be approached in a way that is respectful of their culture, excuse me, and of their background. And people have to be met in their comfort zone. So I think that that's a really, really important role as well, in terms of access to healthcare and working in a partnership.

So let's talk about once somebody has a diagnosis, what do we do. So, there are steroids that are around to help put out a fire, to quiet down active inflammation, whether that's a spot on the MRI that lights up with the IV contrast or whether that's a relapse, something that you exhibit, some new symptom that happens or a symptom that you're very familiar with that increases out of the blue. So, that's what steroids are for, to quiet all that down. Then we have disease modifying therapies. And our disease modifying treatments are to reduce the chance of having new things happen, reduce clinical relapses, reduce MRI spots, to slow down disability progression, really to keep people stable. None of our medicines promise improvement yet. We're not there yet, and I think sometimes people don't think their medicine is really working because you're not getting better. And when a patient comes to me and they say, I'm exactly the same as I was last time I saw you, I get excited. That's the goal. That's truly the goal. People look at me like I'm a little crazy when I say that's great, because I totally understand that you want to be better and to have your MS feel better, do better, because of an MS medicine. But that's not the goal. The goal is to keep you stable.

And then of course symptom management, symptom management for improved quality of life. And I harp on this a lot because many times you don't even know what your symptoms are. And you have to know, you have to know your MS better than anybody else. You cannot let a doctor tell you about your MS, you need to tell the doctor about your MS, because only you know your MS, and only you know your symptoms. You need to know what kind of symptoms you have from your MS. You need to know are you bothered by those symptoms or are you not bothered by those symptoms. If you're bothered, when are you bothered? Does your bladder bother you during the day or is it just a problem at night because you wake up so many times to pee at night that it interrupts your sleep? Some people say to me, you know what, I have bladder urgency. I know I have this symptom. I only want to treat it at nighttime because I should, I really should be sleeping, but during the day it's the only exercise I get. I get up to pee every five minutes, ten minutes. And that's okay. You don't need to touch that. That's great. That's the kind of patient I love to work with, because I want to make their quality of life better, and I want them to tell me what needs to be done. So it's important for you to know your symptoms, know if you want something done about those symptoms, and when you want something done about those symptoms.

It's also important, and really, really your responsibility as well, to make sure that those other comorbid factors are controlled. A healthy body does so much better with MS than a body that is fighting other health conditions. You know, you only have so much energy and your body, your temple, only has so much energy, so much healing power and healing energy. And when it has to be dispersed to so many other conditions, high blood pressure, cholesterol issues, sugar issues, other autoimmune conditions, all of that stuff really, really takes a toll and chips away at your MS, and it's really, really difficult to thrive with your MS when you're combating these other issues as well.

We used to not put so much attention on exercise, sleep, diet. These things are insanely important. I say to my patients, sleep is probably one of the most important things you can do for yourself. Sleep and exercise are when the nervous system repairs the most and when you have new nerves sprouting. Sleep especially. And most of us kind of look at sleep as something to do when everything else is done. Whatever time is left over in the 24 hour clock is devoted to sleep. When you have MS, you have to be very protective of your sleep. Your sleep is really, really important, because again, that's when you heal. It's like a a computer; when your computer gets glitchy, what do we all do? We all just turn it off and reboot it. And that's what we need to do to our nervous system. And I always think about Manhattan, when you go to New York City and you're walking around at night, you see all this trash all around the sidewalks, all around the street. You wake up in the morning and it's just kind of miraculously gone. That's exactly what happens in our brain, the garbage collectors come out and clean up all the trash and all the debris. And if you don't give those garbage collectors enough time to do that, then you're starting your day, and you want those pathways to be clear and open, and there's trash in them, they're glitchy. So there's going to be no speedy electrical impulses flying around because there's debris in the road, there's trash in the streets still. So sleep is really, really important. Insanely important.

And then mental health and stress reduction. This is a tough one. There's a lot of things that we can't always control, like our political situation. There's a lot of stress that we all have to endure. We all live with stress that seems so out of our control. And it definitely impacts our mental health. And mental health and stress issues chip away at MS, and I see people not do so well in my practice, around politics, around election time, around certain things that are kind of happening external to them, in addition to what we're all experiencing with work related stress, financial stress, family stress, and most of those things that we really cannot control. But I'm very, very quick to help people with counseling, with antidepressants or anti-anxiety medicines. I think that those things are really very, very important. And mindfulness meditation techniques, those sorts of things are also really, really important. It's important for you to be able to deal with some of those external factors.

We're realizing more and more that there is under-representation of blacks in most of our medicine clinical trials. So when we're quoting how people do in the clinical trials, when you go to different pharmaceutical dinners and you hear about clinical trial results for a different group for a particular drug, those are usually, almost invariably, the majority of patients in those trials were white. Many of our clinical trials were done in Europe, Eastern Europe, Western Europe, even here in the United States, we don't have a lot of black participation, but the majority of the population from our trials is outside the United States, in European countries. So we have very, very, very little experience in terms of how people of color respond and react with the various medicines we have for MS.

There are some... some of us collect a lot of that data to try to educate on that and to be able to see what medicines people are most successful with, in terms of black and brown MS. So, black experience - very, very different. We knew early on with those injectable products that black and brown people really didn't get the same benefit the white people did. And we saw that pretty early on for a long time. That's all we had, though. That's all that was available. But it's important that we personalize treatment according to somebody's particular needs. And now we have things. You know, it's important to monitor how people are doing with MRI scans. And we have biomarkers. These are... we're starting to use some biomarkers where we can do a blood test, which can tell us, like, how much nervous system trash you have from breakdown of nervous system tissue, how much scarring. We can see that and kind of follow that over time with simple blood test. It's still not quite ready for prime time in terms of telling us where you are in your MS journey. It can just kind of help us know that when you're on a medicine, if we're keeping you stabilized or not, or if you are continuing to have nervous system damage despite being on that medicine. That's really what we use these blood test markers for.

And MRI. MRI is incredibly helpful in terms of predicting somebody’s MS. When I see somebody who has a lot of involvement in their spinal cord, maybe their brain as well, and they are nonwhite, but my exam is good, I get very excited because I know that they may not do so well in the future because their MRIs are really not so great. And so I know if I really jump in with really good medicine, I can make it so that they don't ever, ever catch up to their MRIs. So MRI can be really, really helpful in determining what kind of MS you have, what your MS is like, and how aggressive your MS needs to be treated. And then to have MRIs done periodically when you're on medicine helps us to know whether we're doing a good job, whether we're controlling your MS or whether we're not, and whether you need to have something better. I see people all the time who have had changes in their MRIs and medicines were never changed. They were never provided with something better, more effective, stronger. So it is kind of your your responsibility to know when you have a test done, somebody owes it to you to tell you what that test showed. That is your right.

You kind of think about medicine as a consumer, and you are a consumer of healthcare. You need to go to these appointments with an agenda. You need to have your symptoms at the ready, what you want that doctor to take care of for you. Doctors are working for you, so you need to come prepared. You need to know what you need addressed. You need to be able to say whether a particular treatment you feel is working or not. And if you have any kind of testing done, whether it's blood tests that are done or MRIs that are done, it's important that those results be conveyed to you, that you know what those results are. That's really, really important. You have to be engaged and you have to keep us on our A-game. You have to demand attention to your MS. You deserve it.

So what can you do? You can certainly be prepared. And, sometimes people are being seen in a very short period of time, 15, 20 minute appointments, which is kind of crazy, but that means you have to really, really take charge of that appointment. Otherwise the doc is just going to hijack the appointment. I'll just tell you right now they’re just going to hijack the appointment. You come in there, you got nothing to say, you don't really have any answers to anything, the doc is just going to roll you over with their agenda. So be prepared. Know what's going on with you. Know what you want to convey. Know what medicines you're on. know... please don't ever come in there and say you're on this little red pill, and you take it in the morning or on this little blue pill. You take it at night. Please know your medicines. Please know your doses, when you take them and what those medicines are for. My big joke is you better know all your history. Because if you have a scar on your body somewhere where you had surgery and you don't know what that surgery was for, and I've seen it, people have said, I'm not quite sure what was done there. When we take an organ out of your body, you sure as hell better know about it. So, please know... know you.

And be an advocate for yourself. No one knows your MS better than you, and don't ever forget that. Nobody can tell you about your MS. It's your job to tell us about your MS and what your MS needs. Educate yourself about your particular MS and what your needs are. I think it's important to be a part of an MS community. You're here tonight as a community. I think it's really important. I always think it's important to know people that are like you. When I have patients, you know, young patients, I try to introduce them to somebody young. If I have a black man in their 30s, I make sure I show them another black man in their 30s. If I have, you know, I try to kind of show people like patients. It's pointless to be part of a support group as, you know, as a 30 year old, 25 year old black man, when the support group is mostly 60 year old white women who are empty nesters. You have nothing in common. You can't just have MS in common. It's important to have people around you that look like you, that understand what it is to have MS and to walk in your shoes.

And allow help. This is a big one because people are. We're all pretty bad about asking for help and about allowing help. And remember, it makes you feel good to help other people, and so allow other people that same benefit to feel good by helping you. Nobody's thinking of you as a victim. Nobody's feeling sorry for you. But it's okay to be helped. And it makes people feel really, really, really good when you allow them to help you, especially people that love you. So just keep that in mind.

I am going to stop there and stop talking, because I can talk all night, and kind of maybe think about some questions. I'm going to go to my little Q&A and see where we are with questions.

**Darion Banister:**

Yes. And we thank you. First of all, thank you so much, Dr. Crayton, for sharing just so much knowledge, so much, like, just of your expertise, experience. You've been doing this for a few years now, you know, and still only 25. So I just have to, like, just say that. And we thank you just for sharing all your expertise, your knowledge. But we got several questions that were submitted. And, you know, I just want to start by, you know, like start at the top. Let’s ask them. One question that we got in, what do you believe that MS is directly linked to? And is it stress? Is it environment? Is it genetics? Like, you know, I get that question. It sounds like from, you know, from the person asking, partially it's your expertise, expert opinion and also some of your own, you know, personal how you've seen things maneuver, if you will.

**Dr. Heidi Crayton:**

Yeah. It's all of the above. Fortunately, I always start off by saying fortunately, we don't have to understand why people get MS to have focus on treating MS. That's what's important. But we really do not know why some people get MS and other people don't. We know there's a little bit of genetics, because we know that there's a 20% chance of having MS in a first degree relative. If I have MS, yet identical twins have a 50% chance. Parent to child, less than 3%. There's a little, little, little bit of genetics. We think more and more maybe vitamin D deficiency has something to do with it. And people that didn't really have vitamin D, sunshine, certainly have a higher incidence. We aren't quite sure if there's some infectious something or another that are... that some people's immune systems just kind of react a little crazy with. That's been an ongoing theory. And that infectious agent has always thought to be Epstein-Barr virus, which is the virus that causes mono. Most people with MS have had mono, but not everybody who has mono goes on to have MS. So it's little, little bits and pieces of understanding. But we really don't know. We can't wrap it into a nice little package and say, this is why people get MS.

**Darion Banister:**
Thank you for that.

**Dr. Heidi Crayton:**
But I do want to... I do want everybody to keep in mind though, MS, sometimes people with MS and who have had MS for a really long time think that their immune system is weak, is broken, is pathetic, is not working. That is absolutely not true. That's the opposite. When somebody has MS, their immune system is over the top, is Mighty Mouse. So somebody who has AIDS has no immune system. Somebody with MS has a super duper, duper immune system. And I'm somewhere in the middle here. So everything we do to treat MS is to kind of try to quiet down the immune system response. So we don't want people with MS taking supplements that promote a better, healthier, stronger immune system. So I just like to clarify that point for everybody.

**Darion Banister:**
Thank you for that. So, you know, that kind of brings us to another... Well, sort of similar, in the same aspect, a little bit. I'm thinking about what foods you think should be avoided for someone with MS.

**Dr. Heidi Crayton:**
You know, it's kind of hard. I have a different answer for different people of different ages, because when somebody has toddlers running around the house, there's no way in hell I'm going to tell them, don't eat mac and cheese and hotdogs out of the pot. So, you know, to eat as clean as you possibly can. I'm not at all a fan of some of these big diets being, you know, 100% gluten free. It's less stressful than it used to be. But still, to be 100% keto, some people follow the Terry Wahls diet. You know, there's just not enough kale in the world that I'd be eating all day. So it's really about trying to eat as clean as you can. But my general rule is to eat as much color and crunch as you possibly can. Try to stay away from gray, white food, 30g of fiber a day, two liters of water a day. If you, if we can all do those three things, our temples are going to be very, very happy.

**Darion Banister:**
I love that because your body is your temple. You know, one very important question, I think, is important for folks that are caregivers, that are family, and just our greater community, especially when I think about some of our greater African-American community, as we, you know, we discuss, you know, folks still think that us as black people don't get MS. So, something that someone asked, how can we make sure that we're supporting folks that are living with MS?

**Dr. Heidi Crayton:**

I think the MSAA does a great, great job at supporting African-American MS. In a way that I'm so proud to be a part of, you guys do a phenomenal job, better than I've ever seen, at raising awareness to healthcare providers, as well as people who are living with MS to just open everybody's eyes to say, yes, these are the possibilities and these are the considerations that we all need to have. So, I think the MSAA does a phenomenal job, and that's why we're here tonight.

**Darion Banister:**
Thank you. Thank you so much. And you know, we do this work because of you, because of you all that are here watching, and then just, literally, just having great folks, great champions that are providers doing this great work as well. We are here because of you all. So, you know, another question kind of in the same family, if you will, you know, have can we start more conversations around MS?

**Dr. Heidi Crayton:**
I think that, you know, finding MS communities is really, really important. And I think it's important to, you know, I think that women should have other women. I think men should have men. And then I think, you know, that people should kind of have people in their MS tribe that are somewhat related to their age, just so that you can kind of have somebody who understands what it's like to navigate MS at the place where you are in your life, at the place where you are culturally. I think those things, you know, that's what having a community is all about. And when you have a community, you don't feel so all alone and you feel like you're fighting with other people and not just fighting by yourself. And I think that that's really important to people's health and well-being now more than ever.

**Darion Banister:**
Absolutely. I couldn't agree with you more. You know, we have...

**Dr. Heidi Crayton:**
I see one of the... Oh, go ahead.

**Darion Banister:**
No, go ahead. What were you going to say?

**Dr. Heidi Crayton:**
I see one of these questions in here that actually I wanted to just make a note of because I love complimentary things that kind of help with MS. And there's a question here about acupuncture, and I love acupuncture, I think that our health insurance really does a very, very poor job at helping people with some of these other modes of living successfully with MS. Acupuncture therapy, physical therapy, talk therapy, mental health therapy, those things are really, really important. Acupuncture is one of those that a lot of insurance companies are taking notice of. And now more than ever, many insurance companies actually do cover acupuncture therapy. Maybe you just need a prescription from your healthcare provider. But I love acupuncture therapy to help with muscle spasm, bladder spasticity, fatigue, pain, really important things for living successfully with MS. So...

**Darion Banister:**
You know, thank you so much for, you know, getting us back on topic with a few things. A few medical questions that we have, because we definitely have a few other medical questions I

definitely want to touch on just for a minute. You know, does someone with MS experience memory loss? That's a question for a few folks around that.

**Dr. Heidi Crayton:**
Yeah. That's difficult. That can be kind of a hard topic. It can be, because there's a lot of scarring in the brain. Sometimes I see people that really have a lot of cognitive complaint, but they also don't really sleep. They get no sleep. They survive on 4 or 5 hours of sleep. You cannot expect that your computer is going to function well on 4 or 5 hours of sleep. You throw stress in there and everything just kind of goes to pot. Fatigue, depression also impact cognitive ability. So I'm never quick to just blame MS all by itself. There are some other things that really, really need to be tuned up before we really can say it's 100% just MS, most of us have some other contributory factors as well. But start with sleep.

**Darion Banister:**
That's very good. It's very good to know. You know, speaking of the brain, someone asks, is there a way to stop the development of some brain lesions?

**Dr. Heidi Crayton:**
Yeah. And that's what our better medicines do now. You know, our highly effective therapies, they typically are IV medicines, really do an amazing, amazing job at stopping MS lesions from happening and stopping the progression of MS better than what we had when medicines first came out. So, you know, I certainly opt for those higher efficacy medicines in my black and brown population for sure, because I just want to really put a stop on MS progression, and the medicines we have do that very, very well.

**Darion Banister:**
Speaking of medicines, there was a question about medicines. You know, what type of medicines would you use to aggressively treat a black person living with MS? Are there specific medicines that you think that are, I guess the word is, that you had experience with better success rates among African-Americans than others?

**Dr. Heidi Crayton:**
Yeah. I know it's not appropriate for me to be so assertive in my answer, but I will, because this is the late night crowd. This is the after hours crowd, so I can say whatever I want. I really, truly, in all of my years of treating MS, I feel that TYSABRI does the most effective job with black MS. It is the product that I have the most confidence in to treat black and brown MS. Ocrelizumab is, you know, is another. Ocrelizumab and Briumvi are both newer IV medicines that work very differently. They wipe out B-cells, which are the bullies, the cells that are the bullies, that are causing a lot of craziness to happen. Tysabri doesn't kill any cells, it just prevents them from going into the nervous system and causing problems. But blacks respond to Tysabri very well. And for any black patient in my practice, everybody in my office knows that will be my go to product for black MS.

**Darion Banister:**
That's awesome. That's really good to know. You know, and the other question, you know, we have a few minutes left. Do you feel a person can age and maybe outgrow MS?

**Dr. Heidi Crayton:**
So, we talk about the fact that as we all age, the immune system really, really quiets down. So people in their 70s and 80s maybe get more coughs and colds and things because their

immune system really, really starts to quiet down. So, there's been this big push to think about maybe taking people off of risky medicines as they age, that maybe MS really will quiet down and nothing will really happen as people age, because their immune systems quiet down. Sometimes that's the case, sometimes not. I have found that people that have very, very, very quiet MS throughout their lives, yes, they become even quieter as they age, but sometimes people surprise you. And I've seen people in their 60s who have new things happen with their MS. So, it's really a very, very individual answer. It really depends on a particular individual person's MS. It's not a universal answer.

**Darion Banister:**
True. Very true. You know, I know we only have just a couple more minutes. Okay. I got one more question that I definitely want to ask. Well, technically, two more, but, you know, somebody was just kind of asking about your advice for any African-Americans living with MS to ensure they receive culturally relevant and comprehensive care? What other things, you know, you shared being prepared in the office, but what, you know, what other nuggets can you provide to other folks that don't have the luxury of seeing you?

**Dr. Heidi Crayton:**
I think that, you know, on your site, there's really a lot of good information out there. And there's, you know, I've been part of doing a couple of big projects for the MSAA who cared enough to really put together quite a bit of information about African American MS; just the whole black MS experience. The National MS Society has some of that as well. But I think it's important to look at, you know, educate yourself on what some of those differences are so that you can... in some cases, you're going to be kind of training maybe the medical community that you work with. But don't be shy. You have to be a self advocate. You have to really look out for you, because nobody will look out for your care as much as you need to be. And really demand the best, because you're worth it.

**Darion Banister:**
Yes, absolutely. Couldn't agree more. One final question for you as we wrap up, are you accepting new patients because everyone's been asking, are you taking patients or not? Can people come find you and come see you?

**Dr. Heidi Crayton:**
Yes, I'm taking patients. Yes.

**Darion Banister:**
Awesome! That is so great to hear. Everyone, first of all, I'd like to say thank you once again. We want to thank Dr. Crayton for all of her time providing such informative information, answering questions, and just being available, just having some one-on-one talk with us. Please, before you go, please take a moment and fill out our brief survey. I told you once again, that's going to help us have more conversations like this, being able to bring some more in person to you all, because if any of you all, just a quick, shameless plug, are in Jackson, Mississippi, you'll get a chance to see Dr. Crayton next month in person and live in color. So, please make sure that you all are taking a chance to look at our website to find out all of our events. We have some more educational programs that are coming to you. This will be recorded once again and placed on our website, so you all can take a look and visit, share with your friends, share with your family, share with your greater community. And once again, on behalf of MSAA, all of us here at MSAA, from our presidency, from our advisory boards, from our board

of directors, and all the staff here, we thank you once again. We wish you a happy Black History Month, because we still celebrate. That's not changing.

**Dr. Heidi Crayton:**
That's for damn sure.

**Darion Banister:**
We’ll continue to honor all of our unique cultural differences and celebrate who we are each and every day, and not just in February. Have a good night and thank you all once again.

**Dr. Heidi Crayton:**
Thanks all of you for being here tonight. And thank you, Darion.

**Darion Banister:**
Thank you so much. Until next time, you all, have a good night. Bye.