



Exploring the Landscape of MS in Black Americans

Presented by:
Dr. Mitzi Joi Williams, MD

Marie LeGrand:

Hello and welcome to MSAA's live webinar: Exploring the Landscape of MS in Black Americans. I would like to take this opportunity to thank you for joining us this evening. I am Marie LeGrand, Senior Director of Mission Delivery and Health Equity for MSAA and your host for the program this evening. We are extremely grateful to have Dr. Mitzi Williams with us, who will be presenting on this important topic. Dr. Williams will review findings and provide us with updates on the latest in MS as well as the latest research about MS in the black community. This program is for educational and informational purposes only and does not constitute as formal recommendations. Please do speak with your doctor or health care provider if you have any questions or concerns.

As you may know, MSAA is a national nonprofit organization dedicated to improving lives today for the entire MS community. Some of our free services include a national help line, equipment and cooling products, as well as MRI funding and online community webinars, and many more free programs available to people living with MS all across the country. We have also expanded our helpline hours to 8:00 PM Eastern between Mondays and Thursdays. And to learn more about these and all of the ways in which MSAA improves lives today, please do visit our website at mysaa.org. Or you can also give us a call at 1 (800) 532-7667, extension 154.

Now, throughout tonight's program, you will have the opportunity to ask questions by typing them into the chat box. We do encourage you to submit questions throughout the program, and we will do our very best to answer your questions during the Q&A portion of tonight's webinar. At the end of the program, we ask that you please complete a brief survey. Your feedback is extremely important and will help us in developing future program and content. A link to the survey will also be included in the chat box.

Now, without further ado, I would like to introduce our speaker for this evening. Dr. Mitzi Joi Williams is a neurologist with over 15 years of experience specializing in MS and serves as the founder and CEO of the Joi Life Wellness Group MS Center in Union, Georgia. Dr. Williams has spearheaded and participated in multiple steering committees and work groups to further research in underserved populations with MS. And she also advocates for people living with MS to share in the decision-making process with their health care teams to combat this disease. I will now turn it over to Dr. Williams. Welcome, Dr. Williams.

Dr. Mitzi Joi Williams:

Thank you so much for that introduction, Marie. I hope that everyone's doing well, and I hope everyone can hear me okay. I'm very excited to be here. And thank you so much to MSAA for inviting me to talk about a topic that is very near and dear to my heart, which is MS in the African American community.

All right. So I'm just going to switch over to my slides. And as Marie said, please feel free to drop questions in the chat. And this is meant to be not a comprehensive update because we'd be here for about 6 or 7 hours, if I gave you a full update of everything that was going on, but just meant to be kind of a brief update of some of the interesting things that are going on in MS and updates on some of the research that particularly I am involved in concerning MS in the black population.

All right, so let's get started. So, first hot topic is Epstein Barr Virus and MS. So there's been a lot of buzz about EBV as the possible cause of multiple sclerosis. So, as many of you know, we don't have one thing that we've identified as a cause for MS. We know that certain things increase the risk. We know that, for instance, cigarette smoking increases the risk, we know that low vitamin D increases the risk. We know that genetics play some part, but we know that there is not one thing that we've identified, and something that's been looked at very commonly is viruses, right? Are there viruses that maybe the immune system gets confused with and says maybe this looks a little bit like the myelin or the coating of the nerves, and that's why we see the attack. And so we've always kind of suspected that Epstein Barr virus is associated with multiple sclerosis. But there was a recent study that really suggested that it may be one of the causes of multiple sclerosis.

So what do we know about EBV? Right. It affects about 95% of adults, and most of us have, the vast majority of us, have been exposed to Epstein Barr virus at some point in time. The form of EBV that we're most commonly aware of is called mono or mononucleosis, and it's kind of a viral illness that people have where they're just kind of fatigued and tired and they feel crummy for several weeks. I remember when I was in high school many moons ago, we used to call it the "kissing disease", because people were kissing, but I'm not sure what they call it now, but certainly it's something we've known about for some time, being associated with MS, and what happens is that like many other viruses, once you have that virus, it kind of hangs out in your body for the rest of your life. And normally your immune system is able to kind of keep that under control. And we know that Epstein Barr virus particularly hangs out in the B lymphocytes, those B cells that are part of that immune process. Where myelin is attacked by the immune system. And this most recent study, which is published this year, suggested that Epstein-Barr virus infection may lead to a 32-fold increased risk for developing multiple sclerosis.

Now, it's very interesting data. The difficulty is because it's so common, it's not really clear what we do about that. Right. So there may be, you know, in the future, trials looking at vaccines against Epstein-Barr virus. I'm not sure, but it certainly is very interesting to see that there's a significant correlation between this infection and multiple sclerosis, getting us closer to figuring out what the cause is of this condition.

Now, this was another interesting article, and basically what I did was kind of pick certain articles and things that, you know, had come across my mind, and I'm sure that you guys will have some questions about some. This is a very interesting and important article that was published in JAMA, the Journal of the American Medical Association. And so this is a, you

know, a journal that really has a very far reach in terms of neurologists and other medical practitioners here in the U.S. and abroad. And this article was written by Dr. Lilyana Amezcua, as well as several of her colleagues, and it focused on health disparities and social determinants of health in MS and related disorders. And so the related disorders they particularly looked at was one called in NMO or neuromyelitis optica, which is a disease that's very similar to MS, except it mostly affects the optic nerves and the spinal cord, and there's an antibody for that disease.

However, both of these diseases cause demyelination and can cause the same type of disability. And what they found in this article was that they really tried to look at what we call social determinants of health. You know, so there is this body of data that suggests, and this body of research that suggests that black and Hispanic, Latinx patients people do worse who have MS. And this is very much like what we see in many other conditions. If we think about things like cardiovascular disease, hypertension, etcetera, we know that there are certain populations that do worse. And so, what we really don't know, particularly with MS, is what is the role of social determinants of health, right, where you live, your access to food, other common conditions that you may have, what we call co-morbidities, and in your access to healthcare, access to a neurologist or MS specialist, what role does that piece play versus actual biology. Meaning are there real biologic differences that may lead some populations to have worse outcomes in others? And it's something that we don't really have a good handle on, largely because there is very low representation and diversity in our clinical research.

So this article looked at several things. They looked at socioeconomic status, that's SES, I didn't put that, I didn't spell that all the way out. But that first bullet, it says that low socioeconomic status negatively impacts care in black and Hispanic patients with multiple sclerosis. It also found that black and Hispanic people with MS had higher morbidity. That means more disability and disease and higher mortality. Right? Death rates under the age of 55 were higher in black patients versus white people living with MS. Also, again, it kind of goes back to this question. It's like we see this from the data and the research that we have, but we really don't understand the biological part because there's such low representation and clinical trials of people of color and there are a variety of reasons for that.

And then another thing that I thought was very interesting about this article is that it specifically talked about systemic racism and other forms of discrimination and how that can impact health. And I think that the more we begin to discuss these things, the important, you know, the more common these conversations will be. Right? Because at the end of the day, what we recognize is that black is not an ethnicity, black is a race. Right? And race is what we call a social construct. You know, so there's really not genetic differences that we can say are based on race. And what we have to address is the effects of racism, which do make race a factor in how people do over time with chronic conditions like MS as well as other common conditions.

Now, this was a paper that was published in 2021 with some great colleagues of mine as part of the MS Minority Research Partnership Engagement Network. And that was a project that we started several years ago that was really focused on trying to better understand why we see such low participation in clinical trials and low enrollment in clinical trials. And so we surveyed close to 2600 people living with MS, and you can see the numbers here at the top, there are a little bit over 2000 white patients, 200 black patients and 188 Hispanic patients. And what we found, you know, because the question is if we're seeing this low enrollment, is it because people don't want to be involved or are there other factors that are leading to lower enrollment in trials? And what we found was that there was strong support for research across all of the racial and ethnic groups. So overall, people had very positive outlooks about research. There were

some specific concerns that were raised in minority communities such as things like mistrust and also there was concern that in research, people may receive poor quality of care. There was also a concern about health insurance, and for those who were immigrants, there was concern about legal status, so disclosing that they're an MS patient and how their legal status would be affected if that was documented and recorded somewhere.

So, you know, the other things that really came out of this study were that, you know, people of color weren't asked as commonly to find out about, to participate in studies. And also, people did not know where to find information about clinical trials. And again, you know, clinical trials are not for everyone. Everyone doesn't have to be involved in clinical trials by any means. But it's certainly important to know what your options are so that you can make that informed decision whether you want to or not, and that we don't fully exclude groups of people. One of the ways that I've been really addressing this with my colleagues is to make sure that we focus on there is low representation and not low participation. Because when we say participation, it automatically kind of puts the blame on the person living with the condition that they don't want to participate when in many times we're not asking or we're not asking enough. And so I think that this is really important that this topic is something that's really at the forefront in the MS community, trying to improve this outcome so that we can better understand MS in all populations, and particularly understand why we see some of these differences in the black and Hispanic/LatinX populations versus what we see in some of the other populations.

All right. So let's talk a little bit about two projects that I've been involved in, the National African-American MS registry and the CHIME study. So if you have heard me talk in the last year or so, you've heard me talk about these two projects, but there's been some progress that's been made and we're very excited, you know, that we've had some presentations in some of the congresses over the past year. So the National MS Registry, or NAAMSR, we were able to present a poster at the 2021 ECTRIMS Congress, which is our national, I'm sorry, international MS congress. And we talked about some of the baseline characteristics of people in the registry. So at the time that we presented this data, which was in September or October of last year, we had about 90% female participants and we presented the first 100 surveys. We now have up to 400 people enrolled in the registry and hope to present some data at the upcoming congresses this year. 90% of the patients were female at that time. Most people were in their forties, late forties. Most people had relapsing MS; we could see about 82% of those. And then we had some with secondary progressive or primary progressive MS. Most people were about four years from diagnosis when they were, sorry, they were four years from the time of their first symptom to actual diagnosis. And the majority of people in this study saw a MS neurologist, which is not typical of what we see in the general population.

Interestingly enough, we also asked if people had ever participated in a clinical trial 82% had not. And we asked if people had ever been asked to enroll in a clinical trial, and 84% had not. Which, again, kind of represents this gap, right, either in the way that we're designing our studies or in the way that we're asking, because these people, the majority in this first 100 surveys, have been followed and seen by an MS neurologist. So it's important that if they're not getting asked in a MS neurology clinic, you can imagine what may be happening if they're seeing a general neurologist who may not be running clinical trials.

When we looked at our data from the people who were involved in the registry at that time, the first 100 surveys, almost 20% of patients were not taking any medicine. A disease modifying therapy for their MS, we could see that most of them were on anti B-cell therapies, which are infusions, at the time that we did this, and then there were, there is now an injectable anti B-cell therapy. And then we can see kind of the spread of other therapies that people were on. And so

again, kind of to summarize, 90% of the patients were female, mean age was about 48. There was a delay of about four years from the time of diagnosis to, I'm sorry, for the time of first symptom of MS to diagnosis. And there were about 20, roughly close to 20% who were not taking medicine. And also, there were co-morbidities that were reported among the people in this group which included high cholesterol, high blood pressure, depression, and anxiety.

So conclusions: more women than men, which we expect. There are some studies that suggest that the ratio of female to male with MS and the general population is about three to one, but in the black population some studies have reported it as four to one. So that will kind of go along with that female predominance. Also, there were similar disease subtypes in the registry that we're seeing compared to most other registries. So meaning there wasn't like there was more progressive disease in the African-American registry than what we see with other registries. So that was pretty similar across the board. We talked about the delay in diagnosis. There are other studies that have suggested there's not a delay in diagnosis when everyone has equal access to care. And we saw that nearly 20% of patients had no disease modifying therapy, and about 86% were seen by MS specialists, which may reflect those of us who kind of founded the registry and have really been using it or directing patients to it in our centers. So right now, we don't have as wide a variety of patients who are involved just because of the first group of people who are involved in the registry.

All right. Next, we'll move on and talk a little bit about the CHIME study, which is a really interesting study. It's the first phase IV clinical trial focused on black and Hispanic people living with multiple sclerosis. And this was data that we presented at the Consortium of MS Centers in Orlando in October of 2021. And so, you know, just a little bit of background. When we talk about low representation or low enrollment in clinical trials, we can kind of see some numbers here. So the participation of black and Hispanic patients in clinical trials, for black patients is anywhere from 2% to 16%. And I would say the majority of the studies are more like on the 2% to 5% side of that number. And then for Hispanic/Latinx patients it's roughly 7% or 7.5%. So again, very low enrollment even as compared to what percentage of the population these groups make up.

And when we think about why we see low enrollment in clinical trials, there are a lot of different reasons. Right. So, you know, again, when we talk in the medical community, one of the first ones that people bring up is mistrust, right? Because there is a long, sordid history of unfair and unethical experimentation, especially on black patients throughout the history of the American medical system. However, there are a lot of other barriers that prevent people from being enrolled in clinical trials. And so, you know, some of the systemic barriers that we see are, number one, people are not invited to participate because in the medical community, if we keep saying mistrust, mistrust, mistrust, then people won't want to be involved, you know, people won't ask because they already assume that they know the answer for certain groups of patients, which is not correct, not the correct way to do it.

There often is lack of awareness about where trials are located or how you can get involved in trials, and that can be due to a person's location, if they're not able to get to specialty centers that conduct trials, or the awareness of their neurologists, if their neurologist is not aware of trials that may be conducted in their area.

Also, if we think about socio-cultural factors, especially for people who may immigrate from another place, there may be different perceptions about research. Again, concern of risk to employment and legal status is important, especially for people who are undocumented. Socioeconomic status. Certainly if people are participating in clinical research, you have to take

time off work - who's going to take care of the kids? You know, how are we going to replace this income? How are we going to get to the trial center to participate in these studies? And so there are a lot of factors that can affect a person's ability to participate, and that kind of goes along with financial and logistic burden on the patients. Right. You know, we tell you to be involved in this research, you know, but somebody's got to pay the bills. And so, it can be difficult, especially if there are lots of visits involved where people have to miss work make arrangements for children, etcetera.

And then we talked a little bit about mistrust. And then also when we think about kind of systemic barriers, the way that we as scientists create trials can be problematic. We saw in the last study when we looked at the registry that, you know, black people may have higher comorbidities, things like hypertension, diabetes, other conditions. And so if the way we construct our trials say that you have to be in perfect, 100% health to be in this trial, will automatically exclude large groups of people from our research and will automatically recruit populations that are not realistic in the real world. Right. So we want the research to be good, but we also want it to reflect the people that are living in the real world with this condition and the things that we see on a day to day basis.

So just a little bit about the design of the CHIMES trial. It is closed for enrollment, so we're no longer enrolling in the CHIMES trial, but it was developed in collaboration with multiple partners. And so this is one of the cool things, we think about how can we renovate the way that we do research so that it's more inclusive? I think that this is a great example of that. So the MSAA was involved in helping create the trial. We also had representatives from the Accelerated Cure Project. We had patients who were involved. And we have the Advancing Inclusive Research Council through Roche Genentech involved. And so there are many people who are involved to see how can we make this an inclusive trial so that we get the best results and can get people involved in a safe and effective way.

And basically, we were looking at a particular medication that's already on the market, anti B-cell therapy, and is open label. So we know that everyone's on the medication and we had people who self-identified as black and Hispanic who were 18 to 65 years of age. This is where the study was conducted, primarily in North America. We also had a site in Puerto Rico, and interestingly, we were able to open a site in Africa, in Kenya, and have roughly ten patients from that site, which is the largest group of African patients in any MS study to date.

Other things, we're making sure that we had patient materials reviewed by people living with the condition, make sure that things were translated properly into Spanish so that people could understand and make sure they were giving informed consent. Also, some of the other things, we're looking at compensation for lost earnings. Obviously, you can't pay someone outright to participate in a trial, but also looking at things like travel reimbursement, transportation and child care as well as flexibility so that, you know, people could plan to miss that time from work, etcetera, to participate. Also, we looked at the criteria right? So making sure again, that we don't totally exclude people with comorbidities so that we can try to get the best results possible. And then, and basically we hope to improve our understanding of the biology of MS as well as treatment response, as well as help better increase equity through clinical research.

So before we'll go into kind of the end, I just wanted to touch on a few topics that were of interest at a recent meeting that I went to, and I see that the comments in the chat going up, I hope you guys are putting your questions in there, but I want to touch on a few topics at the meeting I just returned from, which is called ACTRIMS, which is our American congress related to multiple sclerosis. And the theme of this conference, which was held last week in West Palm

Beach, is what we call biomarkers, and biomarkers are basically what we use to try to measure several things. So, is there a test that we can do to determine who's at high risk for MS? Is there a test that we can do to determine who's in the middle of a relapse besides an MRI? Are there other tests that we can use to determine who will do well on this therapy versus who will do well on that therapy? And then finally, are there tests or other things that we can use to determine who has progressive MS or if they're transitioning to progressive MS? The resounding answer to this is that we don't have great biomarkers for these things, but we're understanding more and more about MS.

And there were some very interesting findings that came out of that conference. One of them was there was a lecture that focused on comorbidities, and comorbidities, again, are those other conditions that can affect your health like diabetes, high blood pressure, cardiovascular disease, etcetera. And what they found in one of the opening lectures was that people with at least one cardiovascular comorbidity, meaning like high blood pressure or heart disease, heart failure, etcetera, had an increased risk of progression of MS and also develop disability more quickly. And the number at which they developed a faster progression to needing a cane or walker for MS was very similar to the number that we hear about with black people living with MS. So, you know, again, raises the question, how did these comorbidities affect the course of MS and are we seeing some of these worse outcomes in certain populations primarily because of comorbidities? Or is it some other factor that's related to that?

There were several talks that were focused on genetics and MS, several studies that looked at twins. And there were some factors that suggested that certain family members may have higher risk for MS than others. However, when you look at the general numbers, although we have over 200 different genes that increase risk for MS, what they found was that your risk is still very low. So if you had a certain gene, you know, let's say if you have a first degree relative with MS, your risk for developing MS might be one in 10,000. I'm just throwing a number out here. And if your risk, if you have one of those genes, your risk would increase, but the risk was still extremely small. And we don't know what a lot of the genes actually do. So genetics is something that's being looked into very interesting. But it's very difficult to know what to do with that. And we don't yet have genetic tests that specifically diagnose MS, so to speak.

Next. There were some interesting lectures about stem cell transplant. And when we say stem cell transplant, we're talking about what we call hematopoietic stem cell transplant. So the same type of procedure that is done for people who have cancer. And that type of procedure involves someone receiving, you know, having, you know, some of their cells removed, receiving chemotherapy on the cells being prepared, receiving another round of chemotherapy, and then receiving the cells back. So it's a very rigorous procedure and not the same as some of these other procedures where someone says it stem cell transplant, but they may do a different type of procedure. And so there was some data some long term data that was discussed from a group in Canada. And what they found was that a vast majority of the patients, roughly 70% or 80%, did not have relapses or enhancing activity after they had stem cell transplant. I think one of the difficulties is because the procedure is very rigorous and could cause significant harm to the patient, the question is kind of where does it fit, you know, and how and when should someone be getting stem cell transplant? So there are several studies that are looking at this right now, that we hope to have some results from in the next year or so. So hopefully we'll get some more information about the appropriate people for stem cell transplant. It currently is not considered what we call an approved treatment for MS. But certainly some of our academic centers are doing these procedures. So hopefully we'll have some more information about where this fits and kind of the appropriate people to give this to in the future.

And then finally, MS and the African population, which is very interesting, exciting to me. When we look at the history of MS, we tend to say that MS does not occur in Africa, right. Or places that are, you know, closer to the equator. And although there's not a lot of literature information published, you know, in one of our studies, which I mentioned earlier, we do have roughly ten patients with MS from an African group, and they actually have over 100 patients living with MS. So it'll be very interesting to hear about the characteristics of those patients and hopefully we'll be hearing from more centers in that part of the world to better understand MS in the African population. And I suspect that it's not as uncommon as we think but there may be some difficulties with access to resources, etcetera, that may be leading to lower numbers that we see in our research studies.

So those are Dr. Mitzi's hot topics. Okay, so what do we think about the future? I'm very hopeful. Right? So there's still a lot of work that needs to be done. We have not solved these issues of health disparities by any means, and we're just at the tip of the iceberg in understanding MS in certain populations. But I am very hopeful because there are many people that have brought attention to this topic. Certainly, the MSAA has been doing an amazing job, you know, of putting on programming to help understand MS in the black community, many of our other partners, our other foundations, etc., as well as many researchers are very interested in trying to better understand what's going on so that we can prevent some of these worse outcomes that we're seeing. So I'm very hopeful for the future.

And finally, I always like to end on a note of what can you do to help yourself. So Dr. Williams has given us all this data. Okay, well, you know, what can I do? And so, you know, one of the things that I think is very, very important is empowerment, right? Knowing what you can do to help yourself to help your MS, to help your community or to help your loved ones who are living with MS. So, number one, learn about your diagnosis, right? Your treatment options. You know, many of you who are on this call I know that you're probably staying up to date on different topics and things going on in the MS community, which is extremely important.

Also, once you and your physician come up with a treatment plan, try to stick to it, to the best of your ability. If you're having problems, let someone know so that they can adjust the treatment plan as needed.

The next one is incorporating a healthy diet and exercise into your routine. I get lots of questions all the time about diet and what should I eat Dr. Mitzi to help my MS? And I think we still have a lot that we need to learn about this. There are many who are doing the research to try to better understand different dietary changes that are related to MS. I think we don't have all the answers, but certainly if we think kind of in broad terms, you know, more fresh food than processed food is generally a good way to go. And then every diet kind of has its different spin on that. And I've had many patients that've been very successful with every kind of diet you can think of. So again, consult your doctor before you change your diet or start a diet and then exercising to the best of your ability. Kind of changing the way we think about exercise, exercise does not have to be putting on your whole, you know, Ivy Park outfit and going to work out for, you know, an hour. It could be walking 5 minutes, 10 minutes, doing that several times a day, building up your endurance. But getting that little bit of movement in can help with a lot of different things, can help with mood, can help with some symptoms, like spasticity, can help with constipation, can help get things moving, you know? And so there are a lot of different things that exercise can help, aside from just being a mood booster and helping your cardiovascular health, which is extremely important.

Also, if you have questions or concerns, it's okay to talk to your healthcare team. I encourage my patients to keep a list of things that are going on since the last time we saw them. If there are things that you're concerned about, it does not hurt to call to speak with one of the nursing staff. And they will talk to the doctor and let them know. If it's something you need to come in for, if it's something that may need to continue to just be monitored until the next time you're seen, but it's okay to ask questions.

And then, of course, finding your tribe and your support system is extremely important, right? Because the journey with MS can be difficult, right? So life can be difficult. We're in the middle of a global pandemic, endemic whatever "demic" we're calling it right now. And so you have those stressors and you have regular life stressors. And then when MS kind of rears its head, you got those stressors on top of it. So it's okay to have that support system, okay to take care of your mental health, okay to engage with a mental health provider if you need to. There's nothing wrong with that.

And then finally, my last, well, my second to last bullet. Ask for help when you need it. And this is a problem that many of my patients have and, heck, even I have it sometimes. It's really important to know your limits and when you feel like you're getting to that edge, it's okay to ask for help and it's okay to ask for help before you get there. Right? Oftentimes we have people that are willing to help, but we just feel like we've got to do it on our own and we've got to be super people, but we really don't. And self-care is something that is extremely important for everyone, especially if you're living with a chronic condition that can be affected by stress sometimes.

And then my last bullet is remember that you are your own best advocate, right? So advocating for yourself, you know, making sure that you understand what's going on, making sure that you're in contact with your healthcare team, making sure that you bring somebody with you to your visit, who can maybe report some symptoms that you may have had that you may not have noticed, help you remember what's going on. So you can just focus on that interaction. Again, you are your own best advocate. Knowledge is power. And it's important to take that knowledge and put it to good use.

All right. And then finally, this is my slide to stay connected. I am The Nerdy Neurologist. I've just got on TikTok. I didn't put TikTok on here. You know, I'm struggling, trying to be like the young people on TikTok, but this is where you can find me. I do a lot of advocacy work, a lot of education, focused on MS because I want people to understand, to be empowered about their condition and actively participate in their healthcare team.

And finally, I will end it with my slide for questions. All I need is peace, love and a frickin' cure for multiple sclerosis. Thank you very much for your time and attention and I will hand it back over to Marie to help me moderate some of these questions.

Marie LeGrand:

All right. Well, thank you so much, Dr. Williams. As always, a wonderful, wonderful presentation. So we do have quite a few questions coming in, so I'll go with this one. "I have tried several times to participate in clinical trials. I have been told or received emails that I don't qualify. So basically, how can I participate?"

Dr. Mitzi Joi Williams:

Yeah. So that's a great question. And one of the difficulties is, you know, these trials do sometimes have criteria that people don't fit. One of the biggest problems is that if you have to use some type of assistive device to walk, a cane or a walker, it pretty much automatically excludes you from most clinical trials, which is something I'm actively trying to work on. And also, if you're over a certain age, many of our trials go to age 55. What I would say is that if you can't participate in a clinical trial, it doesn't mean that you can't participate in research. Right? Research comes in a wide variety and forms. So there are registries. There are different surveys. There are some that do exercise interventions. There are some that do diet interventions. So what I would encourage you to do is to look for the MS center that's closest to you. You can also look at web sites like MSAA, the National MS Society also sometimes has a list of active trials and different types of research. But don't be discouraged. Keep trying. But also recognize that you can participate in other forms of research and still make a valuable contribution, even if you don't qualify for the clinical trials that are running at the time when you're applying for those.

Marie LeGrand:

Okay. Another question about clinical trials. "How do I get notified? So if someone is interested in participating, how would they get notified about the clinical trials?"

Dr. Mitzi Joi Williams:

Yes. So it'd be nice if we have some kind of alert system where we could just ping everybody and be like, Hey, there's a trial, but it doesn't quite work like that. Right? So much like this type of information, you kind of have to seek that information. So again, looking at places like, you know, MSAA may have, you know, information about some trials that are going. Also the NMSS. You know, probably the easiest place to look would be to look at a university that's closest to you, especially one that has an MS center because oftentimes our universities or our MS clinics, MS specialty clinics, are running clinical research. And so you can just look on the website, give them a call, call the research department and say, hey, are you running any trials? Most of the practices that I've worked in, when people have called the research department, we've been happy to give them information about the research that we are running on this that's near them. And then again, if you're looking for other ways to participate, like registries, a lot of the information particularly about like the NAAMSR registry would be, you know, on sites like MSAA and National MS Society.

Marie LeGrand:

Wonderful. Thank you. So we're shifting a little bit here, so: "physicians don't listen. They just want to prescribe pills. Why aren't there naturopathic or holistic therapies available or covered by insurance companies?"

Dr. Mitzi Joi Williams:

Right. So physicians are not a monolith. Right? Just like black people are not a monolith. Right? So I have certainly had some people report that they've had that experience. You know, again, when thinking about choosing a healthcare team, it's important to try to find a team that's right for you, right? And I gave an example when I was giving a talk not too long ago, if somebody gave you a really bad haircut, you probably wouldn't keep going to that person and getting bad haircuts. You know, but sometimes when it comes to healthcare providers, we feel like we have to stay in a certain place. Now, everyone does not necessarily have access to an MS specialist. There are many great general neurologists caring for people with MS. But certainly if you don't feel like you're being listened to or heard, it's okay to seek another opinion.

The other thing to keep in mind is that, again, when we think about naturopathic remedies, there are some that my patients have felt have worked really well. But sometimes you can also run into taking a lot of pills, right? They're supplements, but they're still pills. And so I've had some patients who have come in with like 20 bottles. And we've had to kind of sort through and say, you don't need to take all 20 of these, you know. So again, it is still medicine in some form. Right? And it's important to talk to your doctor about complementary alternatives. I have many patients who seek complementary medicine, whether it is acupuncture, etc.. And we sit down and discuss that together. Sometimes it's a good solution for them. Sometimes it's not. You know, I wish I knew why insurance companies don't cover naturopathic you know, services, but they are becoming more open and covering things like acupuncture, like massage therapy. So there definitely has been some movement in terms of, you know, more of what we call complementary medicine being covered by insurance. But there still is a long way to go.

Marie LeGrand:

This is very depressing. "We know there is systemic racism and unconscious bias, but what is being done to combat this issue?"

Dr. Mitzi Joi Williams:

Right. So, again, these talks have really changed over time. So several things that are being done are, again, you look at some of the collectives. I'm not sure what what point that person came in. You know, there is our first research trial that's trying to look and better understand MS. There is a lot of conversation in the MS community and a really collective effort to try to increase diversity in our clinical research and the way that we design trials. But again, that doesn't happen in a week or in a month. You know, and then you also have the challenge that we're in the middle of a global pandemic, which really kind of slows down everything. And so there is a lot of great work that's being done. But this did not happen overnight. We didn't get in it overnight, and we're not going to get out of it overnight. But what I can say is that there are definitely strides, including the registry, including the first trial. And I hope to have even more to report the next time we have this conversation.

Marie LeGrand:

Wonderful. Now, "does MS stop once you reach age past 55?"

Dr. Mitzi Joi Williams:

So if you look at the clinical research, you would think that it would, but it doesn't. And so again, we have to look at the way that we create the clinical research trials. So one of the reasons people stop, the trials often stop at the age of 55 is because as we get older, our immune systems also age. And so, you know, there is a lot of question about what happens to medications. What happens to the effects of medications on our bodies as we age. And you know, when someone often is doing a research trial, they want the data to be as clean as possible. I don't know what other word to use, but meaning you don't have anything that's kind of in the way and you know, making your results difficult to interpret. You know, there are some trials now that are going up to the age of 65, but there are also some research trials looking at what happens to MS over the age of 55 specifically to better understand what happens when we continue medicine, what happens when people stop medicine and hopefully we'll have some research, some data reported out from those trials in the next year or so.

Marie LeGrand:

Right. Okay. So now "how do you know if or when you should change your DMT?"

Dr. Mitzi Joi Williams:

Yes, that's a great question. If I knew the answer to that, I'd probably be a rich woman by now. But in all honesty, there are a couple of things that we look for right? So the way that we determine if a medication is effective are some of the same things that we look at when we look at our clinical research. So the major things that we look at, if any of you have ever gone to a talk about it, MS therapy, or we look at relapses. We look at progression and we look at MRI activity. So those are kind of three things that we look at to determine if a medication is effective in research. But that's also what we look at in real life. The difficulty becomes is that now our medications are so good at stopping relapses in many cases, not in all cases, that it's hard to know if the progression that we see sometimes is because the medicine is just doing such a great job with relapses or if it's kind of breakthrough disease. So it's always an individual conversation that you have with your healthcare provider. And you have that hopefully at every visit. Is what we're doing still working or do we need to move on to something else? And that's a conversation I try to have my patients every time we sit down and talk and then we kind of determine if this is still the right thing to do or if we need to try something else.

Dr. Mitzi Joi Williams:

And then the other reason that people may switch therapy is because they're not able to tolerate it or they have some type of side effect. You know, we now have enough therapies where generally we can find some that treat your MS that you can also tolerate. So, always have the discussion with your doctor at every visit, and then you guys kind of sit down and determine if this is still the right thing to do or if you need to move on to something else.

Marie LeGrand:

Okay. So now still on the topic of medication: "are there any medications that look more promising than others for African-Americans?"

Dr. Mitzi Joi Williams:

So we don't have that data yet. Right? You know, and so there are what we call subanalysis, so when somebody does a clinical trial, they can try to look at certain groups of people that were in the research and determine if they feel like there were differences in response to therapy based on that group of people. For the most part, most of the numbers, in terms of black people in clinical trials, are very low. And when we've looked at some of these subanalysis it seems like people performed pretty equally. But again, there are so few numbers of people in the trials that it's hard to make a determination. Right? So if you have a large clinical trial with 1500 people in it and you got 10 black people or even 15 black people, you can't really make a generalization based off of 10 or 15 people. So there are some other trials with larger numbers that are trying to look at effectiveness, but I think that, you know, we don't have data that suggests that some drugs are better than others in black or Hispanic/Latino populations.

Marie LeGrand:

Okay. So someone had a question about the prevalence of progressive MS compared to relapsing remitting MS in black and LatinX communities. Is there a difference?

Dr. Mitzi Joi Williams:

No. Yeah, so that would be the short answer. No. So we see the same subtypes of MS across black and Hispanic/Latino communities that we see in white populations. So we don't necessarily see more progressive MS in black people. However, we do have studies that suggest that MS progresses faster in black people than in white patients.

Marie LeGrand:

Okay. So we're switching over a little bit to COVID.

Dr. Mitzi Joi Williams:

Okay. I did not talk about COVID.

Marie LeGrand:

Well, you know, there is always that one question that gets in. So "should you get the COVID vaccine if you have MS?"

Dr. Mitzi Joi Williams:

Yes. So again, every decision is an individualized decision with your healthcare provider, it is generally recommended that people with MS get the COVID vaccine.

Marie LeGrand:

Okay. Now, "does MS progress more rapidly in black women?"

Dr. Mitzi Joi Williams:

And black people, yes. So two times faster than in white people. According to some research studies.

Marie LeGrand:

Okay. So "what strategies do you have for helping black Americans to consider a clinical trial?"

Dr. Mitzi Joi Williams:

So in terms of... Say that again Marie, I'm sorry.

Marie LeGrand:

...to participate or even consider being part of a clinical trial.

Dr. Mitzi Joi Williams:

Right. So, again, you know, at the end of the day, I recognize that every single person is not going to be in a clinical trial for a variety of reasons. It may not be feasible depending on how far it is. In some cases, people don't necessarily fit the criteria for clinical research. But I think that it's important for us to consider because it's important for us to have a voice, and you know, many of the myths about research, such as people getting substandard care, just aren't necessarily true. It is access to often cutting edge medicine at top centers with, you know, top specialists who are very well versed in treating MS. Sometimes the care is free, sometimes the medicines are free. And so, again, it should be considered. Doesn't mean that you do it if you read through the criteria and you decide it's not for you. There's nothing wrong with that. But I think that it should at least be part of the conversation that people should be asked, that people should be given the opportunity to participate so that it helps everyone living with MS, you know?

Dr. Mitzi Joi Williams:

And I certainly don't downplay the risks of any type of research, because certainly there are risks and there are side effects, especially if you're talking about medications. So all that needs to be weighed very carefully but I think that it's important for us to at least have the option and for us to at least have the ability to have our voices heard so that we don't have to keep having

the same talks over and over again saying we don't understand, we don't understand, we don't understand because we don't have the research.

Marie LeGrand:

Going to progression, so is there a reason, I know we talked about how MS progresses more quickly in African-Americans, so “is there a reason why it progresses quickly in African-Americans?”

Dr. Mitzi Joi Williams:

Yes. So, again, that's an excellent question. The honest answer is we don't fully know the reason. Again, there's this question of what part does the social determinants of health play? Some studies suggest that diagnosis is delayed. Other studies suggest that diagnosis is around the same time as in white people. So is the issue access to medications? Is the issue access to care? Is the issue bias, and that people's symptoms aren't believed and they aren't put on the appropriate therapy? Is the issue that people don't have access to MS specialists, or is there some underlying biologic issue in a small number of people that makes them do worse? Because we can't say that all black people with MS do poorly. That's absolutely not true. I have many patients that do great on what we would call our less effective medicines, but I do have some patients that have very, very severe disease that progresses very quickly. So in trying to answer that biology versus environment question, you know, clinical research really helps us to better understand that because everybody has access to care. Everybody's getting kind of the same standard of care for the most part. And so it eliminates many of those social determinants of health so that we can better understand if there are biological differences in different groups.

Marie LeGrand:

Wonderful. Now, “do you have any recommendations for those with a significant amount of brain damage?”

Dr. Mitzi Joi Williams:

So I'm not really sure what that means in terms of a significant amount of brain damage. But again, you know, I think when we talk about self-advocacy and self-empowerment it's very important if you do have a disability that's significant related to your MS, meaning it's impairing your ability to function in your everyday life, impairing your ability to work, etc. It's important that not only do you advocate for yourself, but that others and your support team also help you advocate for yourself. Meaning going to those doctor's visits with you, reaching out to your healthcare team if you're having issues and, you know, helping you to articulate the things that are going on so that you can make sure that you have the right treatment plan with your healthcare team.

Marie LeGrand:

Okay. “Are there any new treatments on the horizon for primary progressive MS?”

Dr. Mitzi Joi Williams:

That's a great question. So there are a couple of therapies that are looking at research in primary progressive MS, but there's nothing that's close, meaning like in the next year or so. So we generally have a new drug almost every year for MS. There's nothing that will be out in the next year for primary progressive MS, unfortunately.

Marie LeGrand:

Okay. Ah, let's see here. "I have read MS progression being reversed in European countries. Is that even possible?"

Dr. Mitzi Joi Williams:

So I am not aware of research with reversal of progression, and I guess it would depend on what you mean. So there are some studies where we look at our research outcomes. Those three things that we look at, MRI's, relapses, progression are kind of our traditional measures that we look at. Now studies are, newer studies are looking at other measures to see, number 1, is there improvement, clinically definite improvement is something that we look at. Also, people are looking at shrinkage of the brain. People are now looking at cognitive tests to see if you're thinking improves. And so there are some studies that kind of, what we call anecdotally, suggest that there are some improvement in some patients. The difficulty is that it's hard to know how to weigh that, because oftentimes when people have a relapse, they may see some improvement. So I think it's promising that we are starting to look at these things. I have not seen any studies where there is actual reversal of, significant reversal of like lesions, if that's what you mean by brain damage. But there are studies that are looking at compounds to repair the myelin. We just don't have any that have been approved yet. Hopefully that answers the question.

Marie LeGrand:

Thank you. All right. We'll take one more question. "Why does it take so long for black people to be diagnosed with a MS? It took six years for my diagnosis."

Dr. Mitzi Joi Williams:

Yeah. So that is also an excellent question. And, you know, one of the difficulties is that MS traditionally has been thought of as a disease that occurs in young white women and the symptoms of MS are very common symptoms to other conditions. So if someone sees a young person that has numbness in the arm, you might say pinched nerve, right? The physician has to have that suspicion to look for multiple sclerosis. Now, the MRI's are much more accessible. It is becoming a little bit easier to diagnose, but again, especially if those symptoms disappear or go away, which early symptoms of MS often do, people may not suspect it. So one of the, one of my tasks has been to try to raise awareness and the neurologic community that MS is occurring more commonly in black and Hispanic/Latino populations. And we need to be looking for MS. And so the word is spreading, you know, probably not quickly enough, but hopefully this will be something that will be decreased over time. The delay in diagnosis.

Marie LeGrand:

All right. Well, thank you so much, Dr. Williams. We truly appreciate having you back with us again for another wonderful presentation. This has been an amazing and insightful program. Do you have any last words for viewers?

Dr. Mitzi Joi Williams:

You know, I would say again, thank you all so much for your time and attention. I hope that you continue to arm yourself with education and remember that you are your own best advocate. And I look forward to having even more positive things to report the next time we have this conversation. And thank you to Marie and MSAA for allowing me to speak with you guys tonight.

Marie LeGrand:

Absolutely wonderful. This concludes the webcast. Tonight's webinar was recorded and will be made available on our website at mymsaa.org, you can visit our MSAA calendar of events for

some of our other upcoming webinars. On behalf of MSAA, we would like to once again, thank you, Dr. Williams, for the great presentation. We would also like to thank you for joining us this evening. Please consider completing the brief survey, which will appear on your screen momentarily. Know that we are thinking of the entire MS community and hope that you and your families continue to stay safe. Thank you and have a good night.