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Multiple Sclerosis
Association of America

Navigating Your MS Journey

Presented by:

Dr. Jakai Nolan McEwen

Darion Banister:
All right, everyone, good evening and welcome you to our webinar. Oh excuse me. And at first I have to say happy MSAA... I mean, well, it’s not MSAA’s month, but happy MS awareness month to everyone. We'd like to thank you all for being here. Thank you all for your support. Thank you all for living, thriving, sharing your stories and just being heroes in your community and in this work. We'd like to welcome you to our 2025 MS Awareness Month here at MSAA and we are empowered from the start with MSAA. We're going to talk about navigating your MS journey, and we have a very, very special guest, someone I'm personally a fan of, Doctor Jakai Nolan McEwen. I'm... you all are in for a treat. Please, if you all know someone who needs to be here, if you know someone who needs to hear this later, not only is this being recorded, but get on the phone, text them, call them right now. This is something you don't want to miss. So while I'm getting ready to do some introductions and disclaimers, you have all the time to call everyone to let them know to be here tonight.

I'd like to tell you, my name is Darion Banister, and I serve as the Director of Health Education and Equity here at MSAA. I am here in the lovely city of Atlanta, Georgia, where my colleague, Dr. Jakai Nolan McEwen is as well. And we're going to go ahead and get started and just tell you a little bit about, first, who we are at MSAA. The Multiple Sclerosis Association of America, also the MSAA, it's a little easier, we are a leading resource for the entire MS community. We're improving lives today through vital services and support services like our help line, and you can see our number right here, our 1-800 number, and extension 154. Please don't forget it. If you're in need of service, you're in need of help, you're in need of some programs like our cooling equipment, and I'd like to let you know we're the only MS providers, MS service organization that has a cooling program that runs the entire year. As well as we are proud to announce our MRI access program is back. The only MS organization in this country that is providing service to folks living with MS that are in need of their MRI.

We'd like to thank our generous sponsors for all their support, and we want to let you all know, please tell your friends and take advantage of the services we're offering today. Many other services like these great webinars that are all being recorded and stored on our website and our YouTube channel. And for those of you all that speak Spanish, we can help you and we have services and we can translate any of our printed materials to Spanish for you. Please, to learn more, visit mymsaa.org to learn so many more about our programs, and flip through our files, and just give us a call if you have any other questions we can support you with.

And a few reminders for tonight as we get started. Remember, feel free to submit all of your questions. Dr. Nolan McEwen loves to get questions. She loves to answer. She loves to just share and just be a helpful hand and a wealth of knowledge. Please any questions, let us know what you are thinking, what you may be missing. And remember, she is a renowned neurologist, so y'all might want to just ask a couple questions if you didn't ask somebody else the day before. Today's webinar is going to be recorded and it will be available on demand. Take a look at our video library in the next couple weeks to see this webinar and many more that we've done in the past. And don't forget, this is the most important thing, to complete your survey at the end, to provide your feedback and let us know what's working, what went well and what you want to see. This helps us provide services like this in the future.

A few disclaimers. Remember, this is a program for informational, educational uses only. Although we have a doctor, a neurologist here, this is not specific medical advice. And please contact your provider, your personal provider. Okay? Some of y'all might actually see her, so that may be different for you all to go see her, but if not, please contact your healthcare team and you can ask any questions that we may provide tonight.

And the last thing I have to introduce this amazing, amazing presenter, speaker educator, I don't know, I feel like you're going to be an author one day. It almost came out, so I might be speaking on that. But Dr. Jakai Nolan McEwen is a board certified neurologist and fellowship trained multiple sclerosis specialist here in the Atlanta, Georgia metropolitan area in Smyrna, Georgia, at the Joy Life Wellness Group. FYI, they are accepting new patients. That's a shameless plug, but I'm telling you, she's someone you want to see. She earned her medical degree from Georgia Campus of Philadelphia College and

Osteopathic Medicine in Suwanee, Georgia, and her master's in public health from Emory University. Talk about a Georgia peach. She completed her neurology residency at Kettering Medical Center in Dayton, Ohio. Dr. McEwen also completed a fellowship focused on MS neurology and spasticity management at the Riverside Methodist Hospital in Columbus, Ohio.

While her curiosity regarding neurology stemmed from high school summer programs, multiple sclerosis holds a special place in her life, as she was herself diagnosed with relapsing MS in September 2009. Not only is she an advocate, but she's also one of the leading providers in MS, which is really special to share her story as she continues to advocate for patients and raise awareness in MS. She is the proud co-chair of MSAA’s Black and African-American Advisory Board, and we can't wait to meet and talk to you some more about many programs we have in the future. And without further ado, because I've talked too long, hopefully you all told people to come in the room, present to you all Dr. Jakai Nolan McEwen.

Dr. Jakai Nolan McEwen:
Thank you so much. You are amazing, Darion, I appreciate that. Thank you, thank you, thank you. Hello everyone. I'm looking at the numbers. We are at 90 and counting. I am so excited to see you all here. Please utilize the chat. I see that we have someone from Dallas here. We're glad to have you here as well. And if anyone feels inclined to share where they're from, especially if we have West Coasters online, with me being here... with us being here in the East Coast, I would love to hear that as well, but I like to interact that way also. And of course will be able to chat even further once we get to the end of the presentation. As we go over questions. But just to start a little bit, the goal of today is it’s going to be really laid back. I want to provide education. I want you to leave this feeling like you have learned something new or have been reminded about things in regard to MS. I want you to have a better understanding. We're going to talk about treating and, more importantly, how to live well with MS.

So prior to starting, I do want to share a little bit about my story. So as Darion mentioned, I do have MS as well. I was diagnosed in 2009 after waking up on my very first day of grad school. So when I was first starting at Emory, I woke up and I had blurry vision in my left eye. Now to rewind a little bit, to kind of show you how things tend to happen and how people will just kind of have callings and you're meant to be in a certain place. I have always wanted to be a doctor, and I was actually introduced to neuroscience, or the field of neuroscience, when I was in high school. So I fell in love with everything neuroscience related. I loved that research component of it, at the time. I majored in neuroscience in undergrad and thought that I wanted to be a pediatric neurologist. But then senior year of college came and when it came time to taking my mCAT, which is a test that you take prior to getting into medical school, I kind of chickened out a little bit. I had some imposter syndrome. I was scared to be told no. I didn't think that my grades were good enough. I didn't think that my mCAT score was good enough. In retrospect, it was fine. I should have went ahead and applied. But things happen for a reason.

So, I decided to rather than going onto medical school, kind of figure out my life. I minored in public health. So I decided to move back home to Georgia, and I got into Emory's Master's of Public Health school. On my very first day of school, I woke up with blurry vision in my left eye, and at some point, my left hand was numb as well. And I had always been told by my ophthalmologist that I was at a risk for retinal detachment. And so if I saw any black floaters or any weird changes in my vision that I needed to get to the doctor immediately. So that's what I did that day. I skipped my first day of school and I went to my eye doctor, and he quickly, I guess he saw something concerning, and he sent me to other eye specialists.

And I'll never forget sitting at the end of a hallway and there were two doctors standing at the end of the hallway, I guess speaking about my case, and they were looking at each other and they would look back at me. And then I heard the term multiple sclerosis. So at that time, in undergrad, when we were talking about neuroscience, it was more about like the history of neuroscience. And this is the brain. You have different lobes of your brain. It was not detailed, it wasn't clinical. So I had never heard of MS before. I didn't have any family members, or don't to this day have any other family members or anything with MS, no other friends at the time that I knew with MS. So this was brand new to me. And I look online and of course the first thing I see is someone in a wheelchair and it says this is the number one disabling disease, or chronic disease, for young adults. I freak out, of course I freak out, and I go down the rabbit hole of reading different things. And two weeks later, I officially got a diagnosis of MS after MRI's and all of that, and my way of coping with this newfound part of my life was to throw myself into everything MS related.

So I interned with the National MS Society. I was interning at the CDC for the summer in between my first and second year of grad school, and I kind of focused on things MS related. I did my thesis for grad school about social support, social groups in relation to young adults living with MS. And that was just kind of my way of, I guess, of just kind of coping and learning to process my way through it. I eventually, with all of that, I was like, you know what? What are the odds of me wanting to be a doctor and then wanting to be a neurologist in the time when I'm about to, you know, I'm figuring out my life on what I'm going to do, and I'm almost maybe pushing medicine to the side, boom, I get diagnosed with a neurologic condition? So I took that as this is my calling. This is what I’m meant to do. I applied for medical school, I got in. I continued to love neurology. I did a neurology residency. And then because of my personal history and feeling that I wanted to know the best that I can for myself, but also understand as much as I can for my future patients, I did decide to do a fellowship, where I learned about even more detail of MS and the management of some symptoms that can be associated with MS and other diseases that sometimes look like MS.

So here I am today, and again, I'm very, very happy to be here. Thank you for going through that little journey with me. I just wanted to share so that you understand kind of where I'm coming from. I hope it comes across, my passion for MS and the treatment of MS. I separate myself - I'm patient Jakai and Dr. McEwen, Dr. Nolan McEwen here. So I have the kind of two parts that sometimes they merge, and sometimes I do have to keep them separate. And that part I am working on. But sit back and let's talk a little bit more about MS.

So before we get into it, just from disclosures, I am on several advisory boards, as Darion mentioned, MSAA as a co-chair for the advisory board here, and then other pharmaceutical companies, on advisory boards for them. So what I would like for everyone to get out of our talk today is I want to start with making sure that we're understanding what is MS. Like, what is it doing to your body. What are the key aspects of an MS diagnosis? How does that happen? How do you get your diagnosis? And then we'll move on into talking a little bit about treatment options. Now again I won't go into detail about specific medications, but I'll give you kind of our overlay of the land, with the different options that we have. And then also talk about the importance of early intervention. I would also like for us to learn some ways on how we can manage physical and emotional well-being, and what that means to having a diagnosis of MS. And lastly, just talk about the importance of support, the different types of support that you can have. And then, talk about the resources that are available.

So jumping right into it, what is MS? Some of you here may have MS, you may be a caregiver for someone with MS, you may be a friend of someone with MS, or you might just be here because you want to learn more about MS. We welcome all of that. So I want to break it down a little bit about what is multiple sclerosis or MS. So MS is a chronic disease that affects your central nervous system. It's an autoimmune disease where your body is essentially attacking itself. What I mean by the central nervous system is it’s comprised of three components, primarily, we like to say, the brain and the spinal cord, but also that it also consists of the optic nerve.

So with multiple sclerosis, what happens is, we don't really know the underlying cause, the thought is that perhaps, maybe you're exposed to some sort of virus at some point, and you already have like an underlying small genetic risk of possibly going on to develop MS, and maybe exposed to a virus where like the DNA in this virus is similar to like the DNA or the protein on the wrapping around your nerve cells. Perfect storm happens. And for whatever reason, your body decides to start attacking itself. What it actually attacks is this wrapping around your nerve cells that we call myelin. I like to think about myelin as kind of the wrapping around a wire. So I use the analogy a lot of a cell phone charger. We've all had cell phone chargers where it frays a little bit. At the end you're able to see the wires or the nerves and that, the wrapping around it. We can think of that as the myelin. But whenever it's starting to fray and look a little raggedy, it still works. You plug your phone in, but you might have to position your phone in a particular direction, or it may take a long time to charge your phone.

That's a similar thing that happens once your body, or once the immune system starts attacking the myelin around your nerve cells. It disrupts those nerve signals and makes them go through a lot slower than they're supposed to. And then, because it can affect anywhere in your brain, anywhere in a spinal cord, or again, like I said, your optic nerve, which comes behind your eye, symptoms can vary. They can be more severe or they can be less severe. And MS is a snowflake condition. There will be no two individuals that will have the exact same symptoms happening at the exact same time. There's not like a typical pathway of what we will see in regard to symptoms.

So certain symptoms that we can see with MS, Fatigue. Fatigue is a very common, hidden set of symptoms. A lot of times you may look at someone and you cannot tell that they're tired. Fatigue with MS is a lot different than just kind of your general, Oh, I had a rough day, I'm tired. It’s disabling fatigue, it’s fatigue that you have despite your day to day activities. There's really kind of nothing that you can do. You may hit your wall and once you hit your wall, that's it. You're down for the count. That's a type of fatigue that we can see with MS. Numbness and tingling is another common symptom. With tingling, kind of a sensation of maybe arms, legs, hands or feet being asleep.

Vision problems. So we can see vision loss with optic neuritis, which is basically inflammation of the optic nerve, which comes out the back of your eye, again. And with this you can see painful vision loss. Or it may seem, like, I'll never forget kind of what it was like for me. It did hurt when I was moving my eyes, and then it was like someone took a dirty finger and they put it smack dab in the middle of my eye. It was, you know, it was really weird. Kind of like a veil coming over my eye. Or some people may experience more actual kind of vision loss with their optic neuritis. And then another thing, double vision is another thing that we can see in regard to vision problems.

Walking and balance issues. So if anyone has kind of lesions in the spinal cord, this is often areas that will or could contribute to weakness and on one side of the body or on both arms, both legs and even the numbness and tingling, if someone, if their feet are very numb, that can also contribute to balance issues. And then memory difficulties. I'm not in my head here with this one. This is a major issue for me. The brain fog. You should see me with my patients trying to explain things to them sometimes at the end of the day, and I'm just like, what is this word? I don't know what I'm talking about. Please bear with me. But the brain fog and trouble with word finding, those are things that we can see in regard to memory difficulties.

So types of MS. We're always kind of... the types of MS are always evolving. When you see different things in regard to clinical trials, we may have more specific types of MS, or when we're just kind of talking, maybe in a more professional or a research setting, we may use other terms, but these general types right here, these three here are the main ones that I want you guys to take home with you today. So relapsing-remitting MS, this is the most common type of MS. We have 80 to 85% of people at diagnosis will have relapsing remitting MS. With this type of multiple sclerosis is where you will have flares or relapses that, and if you look in the picture, you can see the blue part on the graph there, where you can have relapses, where you may have onset of neurologic symptoms that maybe increase over a couple of days or a couple of weeks, and then they plateau and then gradually improve with time. It may improve on its own, and definitely use of steroids, which we'll talk about a little bit later, can help that improvement as well. And then you reach your plateau or sometimes you go completely back to baseline or you may have a new baseline with residual symptoms that are left over, but this kind of continues throughout, untreated MS, we'll continue seeing relapses and times of remission over time.

Secondary progressive MS starts off as relapsing-remitting MS, but then as, depending on maybe how long someone has lived with MS, or depending on the type of lesions, where they're located, over time, people will stop noticing that they're having relapses, but then will start to notice more of a progressive decline in or progressive increase in symptoms over time. And then primary progressive MS, this is where you never really have relapses. It's more of just this progressive decline or progressive increase in symptoms over time. So sometimes someone may notice that, you know, sometimes when I get tired, I notice I might drag my leg a little bit. But then just kind of gradually over the years, may notice that this dragging of your leg becomes more consistent. And then it gets to the point where you may need a walker, or so on and so forth, or, you know, gradual progression of having trouble with your hands or tightness in your muscles or spasticity. That's what we primarily see with primary progressive MS.

So how do we diagnose MS? So the key thing, anything in neurology, any neurologist will tell you is, or if you're in the medical field, history. History is going to be important. This is one how we classify or how we give, you know, what type of MS that you have. We want to know your history. A lot of times whenever I have a new patient, especially if they're coming to me already with the diagnosis, I always say, okay, I don't want to start where you are now, let's go back to even before you got your official diagnosis. Now, in retrospect, let's go even further back to symptoms that you may have experienced before that. At the time, you didn't think much of it, but it could have potentially been related to your MS.

I'll give an example for me - my symptoms that led to my diagnosis in 2009 was, again, the optic neuritis and the numbness in my hand. But years before, when I was 15, I actually had onset of a change in my vision in my left eye, where my left eye would not move outwards. So it caused me to have double vision whenever I was looking. I'll never forget, I was in band class and one of my friends came up to me and she was like, your eye looks weird, your eye isn't moving. And we, at the time, like I said, I was 15, I did go to the doctor. I had a CAT scan. I never had an MRI. And my parents, they didn't know about MS. I clearly didn't know about MS. We didn't know the questions to ask or different tests to ask for. So we took what the doctor said that it was just a virus for me to wear an eye patch and that it would improve. I was never given steroids or anything like that. I'm 15, in high school, a freshman in high school, however old you are as a freshman in high school, and I was not wearing an eye patch. I don't think I did it, but it did improve over time. So history is going to be very important with us figuring out, you know, when maybe symptoms first started and then how has the progression or your disease pattern gone over time.

MRI scans. This is another thing that's really important. The MRI, the lesions that we see for MS are very specific in particular locations, and they look a particular way. There are a lot of different conditions that can sometimes look like or mimic MS, and those are things we always want to rule out. You'll see down below we have blood tests. And we can use those things to rule out things that can look like MS in the brain or even in the spinal cord. But there's not a blood test that we can use to say, oh, this is MS, there's not an antibody that we know of yet for a diagnosis of MS. But with the MRI, again, there are particular markers of how the lesions look and where they're located that is very classic for MS. I always like to share my MRI scans with, well not mine, but share an individual's MRI scans with them so that you understand. We don't often count the number of lesions, because some people may have one lesion in a part of the brain that's causing them a lot of issues. And so that one lesion is more important than someone who has a number of lesions in the brain that might not be causing much symptoms. They could be those silent lesions. And at the end of the day it’s more about how are you doing clinically and then what are we going to do to prevent more lesions.

And then sometimes we do need to do a spinal tap or a lumbar puncture. What we're looking for with that, again, it’s another way to rule out potential mimics with multiple sclerosis. But we're also looking to see if there is presence of a protein called oligoclonal bands. So we can see this in greater than 90% of people living with MS. If someone comes back and they don't have presence of these bands, then it would make me want to say, okay, could this be something different? Or if we just see kind of 1 or 2, you know, there again, it just adds to our story with us being able to come up with a diagnosis. But those are the key things - MRI and the examination, spinal tap if necessary, and then we always want to rule out and make sure that we're not potentially missing a different condition.

So why, again, why is it important to diagnose and why is it important to make sure we have the correct diagnosis? And that's because early treatment matters. Brain is time, brain is money, brain is everything. So we want to preserve what we can. I always say that I want to treat your brain right now how we want your brain to treat you in 20, 30, 40, 50 years. So in order to do that, we need to get the correct diagnosis, because with some other conditions that can look like or mimic MS one is NMOSD, or neuromyelitis optica spectrum disorder. Some of the treatments that we have for MS can actually make that worse. So we need to make sure first, yeah, that can make NMO worse. So we need to make sure that we're correctly diagnosing. Another one is called MOGAD or mog antibody disorder. And other autoimmune conditions, sometimes lupus can present with weird lesions in the brain, and different things like that. So again treatment is going to vary. So once we're certain that this is MS, we want to start treatment as soon as possible, because our goal is to reduce the number and severity of relapses. So we know that untreated MS with a natural history is that people are bound to progress; MS is a progressive condition, and that's going to happen if you're not treated. And so we want to make sure that we're doing the best that we can to slow this down. We want to slow down long term disability progression.

So you'll see right down below, we have this scale here, EDSS. This is something that we often will use with research. I like to get it on my patients during first visits. But, it's just a series of things that we're looking at to kind of look more at physical features. It doesn't check things as much like with memory or cognition. But it is better for physical things. And our goal is to keep that EDSS, or expanded disability status scale, to keep that score as low as possible, because you'll see, as the score goes up higher, that's when we're seeing more disability. So at five is when we would say someone, you know, needs to use a cane. Seven is when someone is restricted to a wheelchair. And it goes forth, to being bed bound and different things of that nature. So again, we want to keep that score as low as possible.

And then also we want to protect the brain volume and cognitive function. So the reason behind this is I talked a little bit earlier about how you can have lesions in your brain, but those lesions might be in a position in your brain where they're not causing you any symptoms. That's why a lot of times when someone has their first relapse and we get the brain, there's already multiple lesions there that might not be active, meaning they don't enhance after you're given the contrast. But we know that they've been there for some time. And while they're not causing any issues now, in normal population, everyone, our brain shrinks as we get older. We can't, you know, there's nothing we can do about that. That's just a thing that happens with age. But in untreated multiple sclerosis, the brain shrinks at a quicker rate or faster rate than in the general population. And as you... the lesions that you have there, they might not cause any symptoms because you have enough reserve in other areas of the brain to take over for that one area of the scar tissue, essentially. And what we what we see as your brain naturally shrinks or if your MS is not treated, your brain may shrink a little bit more. And over time that reserve also shrinks. So then it may expose those older lesions that you have. And so that can also be a potential reason for disability and stuff that we're seeing into the future. So when I say protect brain volume, that's the importance behind that. And then, protecting brain volume, that can also help with cognitive function and things of that nature.

So, MS treatment options. So when I'm talking about treatment, there are kind of three different routes that I'm speaking of when I say treatment. So the first one is what do we do when someone has an actual relapse or flare up? With that, we typically treat with steroids. So giving a high dose of steroids helps to calm down the inflammation that's going on that is contributing to your symptoms and helps to calm down inflammation in the body, but then also hopefully helps to get rid of your symptoms as much as possible. Now not everyone, how we mentioned earlier, would go completely back to your original baseline. You may have a new baseline where you might have some residual symptoms, or those symptoms may come out if you get overheated or too cold, or if you get sick or if you're not getting enough sleep. Those are what we call pseudo relapses. But whenever we’re having kind of something concerning for a new lesion in the brain or the spinal cord, we want to treat that was steroids to calm down the inflammation as quickly as possible.

So, then we have disease modifying therapies, or DMTs. So DMTs, what this is doing is we're not there yet with fixing prior damage, so we don't have anything where we're able to remyelinate. There is research going into that now, but we're not quite there yet. And we're not fixing or getting rid of old lesions. The goal with disease modifying therapies is to slow down the progression and to prevent new relapses. The medications that we have now, I tell my patients, if there were ever a time to get diagnosed with MS, if you want to be diagnosed with it, now is the time because the medications we have, they work really, really well. We have over I think we're up to like 25 medications now. And they work really good to the point where we're seeing no evidence of disease activity, meaning that we're not seeing any new lesions on MRI's, and we're not seeing any changes in disability. So that EDSS score, we're talking about, we're not having where people are having more clinical symptoms or, you know, feeling kind of sicker over time. Of course, it's not going to be the case for everyone, but we are seeing large numbers of that with our current disease modifying therapies.

They do come in different formulations. So there are injectable medications. Now, some of the original, or the OG, medications, or what we call platform medications, the majority of neurologists, especially MS specialists, are not going to prescribe those to you. They don't work that well. And then a side effect profile to them sometimes is not worth it, especially when we have ones that work a lot better. But some of our newer medications do come in an injectable form where you inject just under the skin, they come with like an auto injector where you just press the button and they work well. We have oral medications. So again, some of our older medications, depending on how you present, and if you come in hot and you have a lot of symptoms, we may not want to put you on one of these medications just because of the efficacy of them; we have medicines that work better. But, there is absolutely a place for these medications and I still do prescribe them. And then we have infusion therapy. So these are medications that you get through an infusion. It could be once a month. It can be twice a year.

So very, very good options when it comes to disease modifying therapies. And I definitely do... where I want us to discuss, I'll give options that I think are good for you, but I try not to make the decision. At the end of the day, there are factors that you would have to consider. You know, can I travel to get an infusion once a month, or can I even travel to get it twice a year? Do I have an infusion center next to me? Do I have a fear of needles? If we're talking about doing a pill, can you remember to take your pill? Of course, the best medication is going to be the one that you take. So these are all things that come into consideration when, deciding what medication you want to go on. So shared decision making is what I personally believe in.

So we have our medications or the steroids that we use to treat an acute relapse or treat an actual relapse of new symptoms that's going on. We have our DMTs, disease modifying therapies, with the goal is to slow down progression to prevent new lesions, new clinical symptoms. And then we also have medications for symptom relief. Now I have a pill for every ill. But that doesn't mean that I need to give you a medication for all of your symptoms. You know, sometimes it just kind of takes sitting back. I'll use fatigue as an example. We have some great medications that work really well for some people for their MS fatigue. But other people, you know, will realize that physical activity works the best for them. Or we may need to take a step back and say, you're not sleeping at night. That's why you're going to be tired during the day if you're up all night. So... or your vitamin D level is very low, and we know vitamin D is very important with MS. Or you're deficient in vitamin B12. These are all things that can contribute to fatigue. And then other symptoms that people have, again, physical therapy, acupuncture, this is kind of where some more of the natural therapies, or you know, the Western medicine, this is where I kind of put that into the symptom management here and definitely open to conversation in regard to that.

And then a little bit with emerging research. Very, very, very important, I want to talk about participating in clinical trials, especially for my black and brown people online, we are typically not represented much in clinical trials, or research, period. And so there's very... it's difficult to take what is learned in the clinical trials and extrapolate that or compare it to the community for black people with MS or Hispanic people with MS. So we want to make sure that we have people participate in a clinical study so that we know how these medications affect everyone.

Now, are there underlying, you know, factors with how MS presents itself or how it progresses over time? That's a different webinar. And we are seeing some research has shown that there are changes there. And again, are medications the best for everyone in regards to their MS? And we don't know unless we're participating in clinical studies, or it can also be just doing a survey. Or sometimes you can make research work the best for you - if you need help with getting your MRIs, maybe finding a research study that is looking at MRI change over time. Those are free MRIs for you. Or if you need a free drug, you know, studies that are looking at a particular drug that you want. So these are things that you can bring up with your, MS specialist or your neurologist, and I'm sure they will be able to guide you in a direction for that.

And then there are always research on new treatments. We are working very hard to find new medications that help to maybe reverse things that we're seeing with MS, but also slow down things like with primary-progressive MS. Our current medications don't work the best for primary-progressive MS, they work a little bit better, or a lot better, I should say, for relapsing remitting MS. So, we're trying to find medications that, you know, that work well for everything. And then also we have lifestyle modifications. And this is one that I think is huge. I put this under management for symptom relief, but definitely want to go into a little bit more detail about what I mean by that.

So the first one: staying physically healthy. This is huge. This is very, very important. We know from clinical studies that when you're physically active, this actually helps your brain cells to make new connections. So once in the central nervous system, so again in your brain or your spinal cord, once there are damage to those nerve cells, they don't come back. That damage is done and there's nothing, at this time, that we can do to to repair that or make that damage go away. But those nerve cells, even if they are, you know, slightly damaged, the part that's damaged is not going to change, but there can be new branches that come off or new tentacles, so you can think about it. So, we've seen that in clinical trials where physical activity helps to contribute to that.

So what that means for you, it means, you know, whatever you're able to do. Exercise and movement is going to be very, very key. So if yoga is something that just works well for what you're able to do, swimming or stretching, these are all things to consider. I think stretching is huge, especially if you suffer from spasticity or tight muscles, that can be key to helping with that. But more so just kind of listening to your body. A lot of questions I will get is, you know, can I exercise if I have MS? You know, my MS acts up when I get overheated, so I don't want to set myself back if I do that. And I always say, yes, you can, but you just may have to do it in a different way. Or again, just kind of listen to your body or there are trainers who specialize in management for physical therapy and exercise programs for those living specifically with MS or other autoimmune conditions.

Nutrition and diet, it's going to be another thing that's important. There are a lot of diets out there that have shown promise with MS, but nothing that we've shown that can actually slow down the progression in clinical trials, slow down the progression or change the underlying nature of MS, especially if someone decides not to go on a disease modifying therapy. So what I typically recommend is just a heart healthy diet. If it makes you feel good, if you're doing something to protect your heart, you're automatically protecting your brain, and vice versa. So heart healthy diet is going to be the main thing that I would recommend.

Sleep. This is a time when your body is resetting itself. So we want to make sure that we get good sleep. We know that not getting to sleep can contribute to fatigue. It can also contribute to things like brain fog. So I always like to go over good sleep habits and making sure that we're knowing kind of, again, when to listen to our body and when it's just like, I can't do that. I worked really hard yesterday or two days before, and I know in two days or three days or next week I might crash a little bit. So being okay with saying no, making sure that your loved ones, your friends, if you're comfortable sharing with your coworkers that, you know, if you're having an off day that, you know, it's okay, just listen to your body and do what you need to do.

No smoking. This is another huge one. We know that smoking actually hastens the progression of MS almost by 50%. So, even for secondhand smoking, that's also... it's something that can also worsen the progression of it. So trying to avoid smoking by all means is going to be critical. And then I mentioned a little bit earlier about vitamin D. So we know that low levels of vitamin D increase the risk of getting MS, and then also once you have MS, if your levels of vitamin D are low, that can also hasten the progression. This is also in an untreated MS, but even in those who are being properly treated with like a disease modifying therapy, I always like to have higher vitamin D levels. I personally like to see them between 50 and 100. We do have to be careful with vitamin D, whereas with vitamin B12 you can take that to your heart's desire. Is water soluble, meaning that you get too much of it, you'll just pee it out. But with vitamin D, it can actually start to affect your vitamin C and affect your bones if the levels are too high. So we do monitor that. But vitamin D is very important. Also going back up to nutrition, gut health, there's a lot of research going into gut health and how that is potentially playing a role with the onset of MS and then overall management of it. So a lot of interesting studies going into that now.

So managing emotional health, now this is one of the things that this starts on our journey when we receive that first diagnosis, it can be overwhelming. You're charting into new territory. You're living with a chronic condition, a chronic disease that can be unknown, even if you're doing the best that you can. If you're in agreeance with your neurologist and you're doing everything that's recommended, there is always kind of in the back of your mind of that, you know, that kind of unknowns factor, I get it. And that in itself can cause, you know, mental health challenges that wax and wane over time. And we do tend to see, you know, that peak, of course, when you're first diagnosed. So anxiety, depression, “why me”s, the stress of trying to figure out your new life, all those things can take and play a role on you and these things can contribute to cognitive changes. It can also contribute to your fatigue or contributing just to how you’re functioning, it can cause worsening of symptoms that you may have had from a prior relapse. So it's very, very important to... I always like to give referrals to a therapist if someone is open to it. Sometimes you just need to talk it out.

And, you know, social support is going to also be, you know, critical throughout all stages, whether you're newly diagnosed or you've been living with MS for 30 years. You know, it's going to be critical to have that support system. Now, whether you find that in your family or in your friends or you go out and you like to engage with support groups, whether it's online or in person, I think that is going to be critical. We're humans. We are naturally social beings. And even if you're an introvert, you know, you might... I remember when I was first diagnosed, I did not feel comfortable going to actual support group meetings. It was, I don't know if I wanted to see the possibilities for me. I'll be blunt with you. And so I found reprising around that time is when Instagram was coming out and I, you know, was looking and I was looking and seeing what other people were doing and, you know, different patient groups. And like I said, with the National MS Society, that is kind of how at that time I sought out social support outside of my family.

And then coping strategies. Whatever works for you; however you found a way to cope prior to getting diagnosed with MS, that's shouldn’t change with MS, MS should not change who you are innately. So if mindfulness works for you, I like to recommend the Calm app, that could be very helpful. I mentioned earlier therapy journaling. I kind of go to this on nights where my anxiety is like at an all time high. I'm a new mom. I still say new, my son's 20 months now, but I guess that's still a new mom. And sometimes I just wake up and I just have all these thoughts running through my mind, and I can't fall back asleep. And I know it's just anxiety. But what I do is I'll get my phone out or I'll get, like, a little notepad, and I just kind of write down everything that I need to do or my thoughts to kind of just throw it out there. There’s nothing that I can do about it at that moment, so let me get it out my mind. And sometimes, a lot of times that helps me fall back asleep. Sometimes it doesn't, but sometimes it does. But other just kind of journaling, you know, day to day that can be very helpful for some people. So managing emotional health is an important thing to consider all throughout whether you're newly diagnosed or, again, you've been diagnosed for several years.

So again, I'm going to keep coming to building a support system. You do not have to go through this alone. You should not go through this alone. There may be some of you online and, what's the new saying on TikTok? We listen and we don't judge. I'm not judging you. If you do not feel comfortable sharing with maybe your children or even a spouse or your parents, but whoever you do feel comfortable sharing with, I want you to kind of lean in on that support for you, and I hope that you're able to get to the point where you're comfortable sharing with, you know, your other love roles. But family, care partners and friends, they can play a crucial role in your daily life.

And regardless of, kind of, if you don't have many physical symptoms or if you do have more physical symptoms, there's always going to be a role for them, whether it’s reminding you to take your medication or, you know, just checking in on you to see, you know, how you're doing, or, you know, helping you get to and from appointments, it's going to be crucial to kind of have that network there. Connecting with MS communities like MSAA, that helps to provide encouragement and advice. Online forums, in-person groups, I'm loving, I'm glad that we're, you know, starting to be able to get back to the point where we're having more in-person things, but absolutely there are places for webinars, you know, with this where we're able to have people from all over the country on here. So, you know, that's amazing and offers, you know, the ability to have that additional support.

And I put your healthcare team here at the bottom, not saying that we're not important, that me as your neurologist, your MS specialist, I'm not important, but I put healthcare team at the bottom because we can help with all of those things above. We can help connect you with different, you know, online groups or, you know, various MS communities who can help provide resources for you. If you're comfortable bringing family members or friends to an appointment, we can sit down and explain what it is that you're going through, what MS is if you are not comfortable with explaining what's going on with your body. You know, so if you allow us to come in and we are able to find ways to help you build that support system.

Okay. And then resources, there are multitude of resources. We can also provide access for this. And coming to events like this, again, there are national MS organizations who provide education materials. There are online tools and apps to help track symptoms and treatments. With one of the medications I was taking when I was first diagnosed, I would use an app to keep up with the site where, it was an injection, to keep up with the site where I gave my injection so that I wouldn't do the same thing next time. So there are a lot of tools that can help.

Financial insurance guidance. Please, please, please be open with your neurologist. You know, if you know that there might be a lapse in your insurance, we can help get you in contact with the pharmaceutical company that makes your medication to get you free drug while you're in the lapse of your insurance. We can't help with what we don't know, so please be open. Come with questions to your appointments, and we're there to guide you. And then workplace accommodations. It's not necessary to disclose that you have MS in your workplace, but if it gets to the point where accommodations will be beneficial for you, I absolutely recommend at least talking with HR or to your direct manager. Or if you are the manager, talk to whoever you need to talk to to make sure that you have what you need in your workplace, whether it's even FMLA or, you know, making sure that you have, if you're in a wheelchair or you need to use a wheelchair from time to time, that you have the appropriate access to get to where you need to get.

And then lastly, I want to make sure that we have time for questions. So my key takeaways, I'm sorry I rambled a little bit today, but I'm okay with staying on a little bit longer if we need to. I'm sorry to the MSAA staff to pull that out there, but, key takeaways from today: Early treatment is crucial. We want to preserve your brain the best that we can, prevent new symptoms, manage your symptoms the best that we can. Lifestyle choices will impact your well-being. We talked about the importance of building a strong support system, that will carry you through more than you know. Your family members and your friends, they'll notice things about you that you might not even notice. They might be like, hey, you know, you're dragging that foot a little bit, are you okay? Or my dad will point out, you're shaking a little bit. You okay? So they're going to notice things that you're not going to pay attention to at all. And then the important part is staying informed, being proactive. We know that knowledge is power and action changes lives. So thank you all so much again for listening to me ramble on. And I'll pass it back over to Darion for questions.

Darion Banister:
Thank you. Thank you all so much. And you know you are never rambling. I learn something every time I listen to you. I can't tell you how many folks have already just commented on like the wonderful presentation. They're looking forward to the recording and we have so many

questions. So, trying to be respectful of time. So if you're willing we can say a few minutes later. But I definitely want to be respectful of everyone's time here. But, we have so many questions about, you know, what are just some other things folks can do besides, you know, your traditional medicine, your traditional treatment?

Dr. Jakai Nolan McEwen:

So when it comes to managing the underlying, so your immune system, and what your immune system is doing to your body, that's where the medications, so those disease modifying therapies, come in. But when we are talking about managing symptoms and quality of life, that's where things like acupuncture, I am like a huge pusher and proponent for acupuncture. Physical therapy. A lot of times, especially if someone has any kind of changes in their spinal cord that affects their arms or their legs, they may sometimes develop tightness or spasticity. Pain is often it's also a symptom of MS that we don't talk about as much. And that's where things, again, like acupuncture or even the medical marijuana can come into play that, you know, again, just help with people's quality of life. These medications... or not medications... these treatments are not going to change what your immune system is doing, but it's going to affect how you feel day to day. So I am a proponent for it. I always recommend, you know, if there's something you find, take it with you to your appointment, talk to your neurologist about it and, you know, get their opinion. And, you know, as long as it doesn't hurt you, as long as it doesn't enhance your immune system, we don't want to do that, your immune system is already overactive, as long as it doesn't enhance your immune system, I say go for it.

Darion Banister:

Awesome. Thank you for that. And you know, a few other questions kind of around medicine in the same vein and just, you know, different things to do: What are maybe some new things that may be on the horizon to, you know, you are quite involved with research, new infusions, new techniques, even as you talked about research, how can folks, you know, also get in research that you mentioned?

Dr. Jakai Nolan McEwen:

Yes, absolutely. So I'll start with kind of the research question. So there are, looking online, you can even go to, I know that it’s on MSAA’s website, where you can find resources for different clinical trials and stuff that are going on. You can talk with, I think the biggest thing would be to speak to your neurologist. And sometimes we're in areas where there are not any clinical trials going on specifically there. But they will know a way to get you in contact with it. So I will start with talk to your neurologist about it. And, or you can kind of just look online to see different programs for that.

In regard to things that are on the horizon. There is a new type of medication that we're studying, what we call BTK inhibitors. The thought behind this is that these medications, we hope, help more with kind of like that smoldering inflammation that's going on even beyond like when people are stable for years, but they're still just like, I’m just like getting worse and, you know, I'm not feeling as well. We think that there is this underlying smoldering information that our MRI's are not good enough to detect yet, and the hope is that this medication can help some with that. We've had issues with tolerability, so side effects. There was one that did kind of make it through a phase three clinical trial, and it just didn't hit the mark like we wanted it to. But there are others still on the horizon that hopefully we'll be able to kind of introduce to everyone in the next couple of years.

Darion Banister:

That is amazing. And, you know, as we talk about medicine, you know, folks are, you know, asking questions because, you know, many folks, you know, may not just have MS, there may be some other comorbidities going on, like folks may have high blood pressure, diabetes, ADHD, weight loss, like, you know, folks are kind of curious are some of the other, you know, popular drugs that they may be prescribed by, let's say, their primary care or for other things that are going on, how well will they relate to, like, some of the MS medicines? Like, will there be a long term effect? Will that progress folks? Like, you know, what is your expertise and experience around some of those?

Dr. Jakai Nolan McEwen:
So for a majority of, you know, other conditions, medications and things, there are very few that are going to make your MS worse. Now, for some autoimmune conditions, there are some medications that don't play well with MS. Medications, because they increase the parts of the immune system that we suspect are attacking your body in MS. So those medications we would recommend avoiding and that will be something typically like a rheumatologist or someone would prescribe. So, it will be an autoimmune condition like that. But, the majority of the time, you know, medications are not going to harm you. People, you know, they talk about different surgeries, you know, it's not going to affect your MS or anything like that. I always say that MS is not the underlying cause of every medical condition that you have. I always want everyone to recognize that even if you have MS, you can still have diabetes, underlying diabetes, you can still have high blood pressure. And all these things are just as important to manage properly as your MS. So, definitely important to kind of continue close, follow up with your family doctor. And some symptoms that you can see from other conditions can make your MS appear or make your MS symptoms seem worse. So, we always want to kind of work together to manage you as a whole and not just focus on just one condition.

Darion Banister:
Awesome. I love that that goes back to our care team. You know, there's more than just, you know, you being the patient. There's more than just you and your neurologist who's great, but you also have so many other folks. You have your primary care, ObGyn. I love when we talk about not only shared decision making, but your care team as a whole. Like, we all have the care team, we need to make sure, we need to increase our care team and really put them to work. And they're working for us, they’re supporting us and just being authentic and awesome. So thank you for that. You know, one question as folks are, as we as people, you know, we're living to be older, we're becoming more seasoned. And, you know, you know, I feel like, you know where I'm going, but this is a question that, you know, we keep getting and I have to just bring it up. So, you go ahead and tell me your opinion. Folks are wondering if and when you should stop taking, you know, medicine for your MS?

Dr. Jakai Nolan McEwen:
Absolutely. Yes. This question comes up all the time. So of course it's going to be specific on you. So talk with your neurologist about that. But this is a hot topic in the field. Like, there are, like... what am I trying to say? There are downright, like, almost brawls talking about the right thing to do, you know, when we have our different conferences and things of that nature. So the idea is that everyone, as we get older, MS or not, our immune system kind of calms down as we get a little bit older. And so it's not as overactive. It's not attacking your body in someone with MS as much as it may have, you know, when you were diagnosed at a younger age. So the thought is that, especially with some of our medications that might modify the immune system in a way with, say, affecting your B cells or different things like that, we want to be very careful to make sure that we're not modifying the immune system too much where it can cause an

increase in symptoms, so it can cause, you know, increase in infections and things of that nature.

So it does depend on the medication that someone is on if I'm going to recommend, you know, switching their medication or stopping. If someone has been very stable for many years, I usually would start having these conversations like 65 and above, or are we going to come off a medication, or are we maybe going to go to a different medication that could be like our endgame medicine, where you might take it for a certain amount of time and then that's it. And we just monitor. So there's a lot of, thankfully, now with the medications we have, there are different options on ways to go about that. So definitely something to bring up. If you're not comfortable being on a medication, I think it's fair to bring it up with your neurologist and have an open dialog about it. Just know everyone is going to have their own separate opinion. But you know, it's your body. And at the end of the day, you should be able to decide what you want to do with your body. Did I answer that without answering it?

Darion Banister:
I think you did. I think you did a fair job. I definitely think you did a fair job. Remember we had disclaimers earlier. So this is once again, this is just educational purposes. And you know, you can talk to your specific provider on that. And you know, as we keep talking about some of these hot issues, it's another one that it keeps coming up. So I'm very inclined to have to put this to you. Folks are always asking about vaccines, especially, we're talking a lot more about vaccines, you know, since COVID, and, you know, the thought about, you know, are certain vaccines helpful or harmful? Long term effects? So kind of giving us your thoughts and experience, you know, specifically for our community, for folks that live with MS. Vaccines? Your take on it.

Dr. Jakai Nolan McEwen:
Absolutely. So, I would say vaccines are safe, with the exception of the... and also depending on the medication that you're on. So if you're on a medication that slightly suppresses your immune system, so I, I is it okay? It's okay for me to say names of medicines, right?

Darion Banister:
People have been saying... Hey, disclaimer. So, go for it.

Dr. Jakai Nolan McEwen:
Okay, so I'll just give an example of OCREVUS, which is an, a medication that slightly suppresses your immune system, in a sense, by knocking out a subset of your B cells, which is a part of your white blood cells, which is a part of your immune system. So the thought behind that is, if we give a vaccine that's a live vaccine, then that can kind of, you're not going to have as much of your immune system to kind of make sure that this live vaccine doesn't actually cause what we're trying to prevent. But with un-live, or killed vaccines or different things like that, that's not an issue or anything, and those concerns. It more comes down to, again, the medication that you're taking and what the medicine is doing to your immune system. So I'll use OCREVUS again. We want to make sure that when we're doing some vaccines like this, we'll say flu, flu vaccine, that we're doing it at an opportune time where it's not right after you get your infusion, where your B cells might be a little bit lower, we want to make sure that your body is able to mount up the proper response. So it might be, you know, if we're able to time up that vaccine before you take your medicine. So it does come down to the medications that you're on.

But in general, vaccines are safe with MS. We're not typically seeing, you know, them causing relapses or anything like that. Now, the COVID vaccine, that's a whole other thing. We're not gonna go down that road. But, you know, I'll give my, my own experience with it. COVID vaccines, I got all of them. I got my boosters and all of that. But every single time I felt like I had COVID, and because I was sick from it, it would cause me to just be more fatigued. And, you know, my brain fog that I talked about, you know, some of those symptoms would come out a little bit more. So those are things that we look at. And, you know, again, talking with your family doctor and your neurologist, you know, to see if you will be a good candidate for it. But in general, they are safe.

Darion Banister:
Awesome. Thank you. One other question that I would definitely be remiss if I didn't ask this and share this. This is part of the reason we decided to come up with this in the title, Empowered from the Start, because really, we want to talk about folks that are newly diagnosed and, you know, how folks are navigating through their journey, something that's come up here and then and just in general, questions are asking, you know, at diagnosis, folks are stricken with grief. How do you process, how do you take the information, you know, deal with it how you want, how you need, how you... and then continue to move forward?

Dr. Jakai Nolan McEwen:
Absolutely. It can be difficult. I'll be honest. I remember when I was diagnosed, so I'm in grad school, I'm living near, I wasn't on campus, but I was living near Emory's campus. And so I would see people riding on their bikes to school, and I would just get, I would get down. Sometimes I would get mad. I would have days where I'd be mad at that person. I'm just like, what if I can't get up and I might not be able to do that tomorrow? Like, it was all those things kind of going through my mind and it was, you know, ups and downs. I might be angry one day. I'm sad the other day. The “why me”s? I'm just starting off my life. Like, what is going on? But, as I learned more about MS, how it works, how we manage it... I think education. So educating yourself on what MS is and what the management looks like to you is a good way of kind of coping, because the more you know, again, we talked about knowledge is power. So the more you know the easier it is where you might not necessarily freak out over little small things. You're like, oh my goodness, my shoulder hurts. Is this my MS? Like, you know that MS is not typically going to affect your shoulder. You know that's your joint, MS doesn't do that. So it can help ease your mind in that sense. But other than that, just leaning into it, you know, this is... I recommend kind of don't shy away from it. You know, it's okay if you go through that initial process of denial. Again, we're all human. But once you go through your stages of grief, kind of pick yourself up and, you know, do what you need to do with the medications, seek out help from a therapist. Lean on your family, lean on your friends, lean on your social network, whether it's other people with MS, coming to, you know, events and stuff like this, I think that's the best way to cope. It’s going to look different for everyone and it's going to take some time.

I have kind of compartmentalized myself. I have Dr. Nolan McEwen here, and then I have Jakai here. And, you know, I tend to be okay in this zone over here as the doctor, but I was doing an event with one of my friends within the field, and we were supposed to just be kind of chatting and, you know, with her as a doctor, me more as the patient. And she, all she did was ask me, how are you doing? I just started crying because I'm used to being the one asking how you're doing? I had to kind of put myself back into that seat. So even though I've been diagnosed now for 15 years, you know you're going to have that up and down where, you know, you just need to take a moment, cry it out, and then, you know, be like, I've got this. You know, I'm doing the best that I can, I’m managing my symptoms the best that I know how, the best at my doctors and, you know, other providers are telling me and I'm doing the best that I can with regards to my medication, it works well for me, I'm able to actually take the medicine. And just know that you're doing the best you can and that's all you can do.

Darion Banister:
Thank you so much. First and foremost, as we come to a close, I have to thank you, thank you, thank you on behalf of all of us here at MSAA, from the board to the entire staff, to all the advocates that we work with, all the advisory boards that you support and serve, like, we are just so grateful to just have you to work with you, to know you, to support you, to follow you. Thank you for sharing your story. Thank you for being the champion. You know, for folks that that that don't have the opportunity to speak and to let their voices be heard and to answer questions and folks that don't even know how to ask the right questions that are just having thoughts. You just do so much just by being who you are and showing up in these rooms. And I had to just let you know that it does not go unnoticed for all of us here at MSAA, all of us that are living with MS, in the community, in the country that are here, we thank you all for joining us. Please, everyone, join me in thanking Dr. Jakai Nolan McEwen. What I told you? The rock star and amazing world renowned neurologist, I'm telling you, this is someone you want to watch. If you haven't, you're going to see her on CNN on the news. I guarantee it very, very soon for all of her amazing work.

But please, thank you once again. It's been a great celebration. As we come to a close of MS Awareness Month 2025, we did it you all. We have made it through March and we are closing now with a bang. Please remember if you have not done so to take a moment to complete that survey, it's really important so we can have folks like Dr. McEwen coming back and sharing more and taking her all over so we can bring her to your community, because she does travel and she loves to give presentations, talk, and you see that she's wonderful and amazing and also very timely no matter what. Thank you so much. If you have any questions for us, please contact us. Our phone number is there, general information, website, all of our socials. We're on everything and be on the lookout in the next few weeks for this to be posted online. Share with everyone. Thank you, thank you, thank you again and have a great night everyone.

Dr. Jakai Nolan McEwen:
Thank you everyone so much. Clap for you for making it tonight.

Darion Banister:
We made it! Everyone, you have a wonderful night and we will see you next time. Thanks again.