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Multiple Sclerosis Association of America

Advocacy Starts with You

Presented by:
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Yahaira Rivera
Hi, everyone, and welcome. Thank you so much for joining our MS Awareness Month webinar, Advocacy Starts with You. My name is Yahaira Rivera, and I'm Senior Director of Health Education and Healthcare Relations for MSAA, and I'll be your host. Today's conversation is a very candid and meaningful one. We'll be exploring the power of self-advocacy. What it really means, what it can look like in everyday life, and practical ways to implement it across different settings.

Joining me today, we have two incredible speakers, Dr. Erica Rivas, an MS specialist, and Anita Williams, a lived experience expert and dedicated advocate. Together, they bring both the clinical expertise and personal insights to this conversation, sharing perspectives from the healthcare settings and from life with multiple sclerosis. And during MS Awareness Month, the Multiple Sclerosis Association of America remains dedicated to improving lives today through vital services and compassionate support. To learn more about all of our programs and services, please visit mymsaa.org.

And I would also like to encourage you to stay connected with MSAA. You can sign up to receive e-mail updates, follow us on all the social media platforms, and now you can also text MSAA to 75101, and you'll receive MS-related news, updates about programs and events, and you can learn ways to support the MS community.

Before we begin, this is just a friendly reminder that this program is for educational and informational purposes only and does not constitute any formal recommendations. Please be sure to speak with your healthcare provider about any specific questions or concerns. And now it is my pleasure to introduce our guest speakers.

First, we welcome Anita Williams, a lived experience expert and dedicated advocate. She's an active member of the Minority Research Engagement Partnership Network, iConquerMS RIDE Council, and MSAA's MS Implementation Network. We are also joined by Dr. Erica Rivas, an MS specialist. An expert in immunological conditions, she has authored multiple scientific publications on multiple sclerosis and served on MSAA's Hispanic and Latinx Advisory Council.

Welcome, Anita, and welcome, Dr. Rivas. Thank you so much for being part of this important conversation.

Anita Williams

First, thank you for having me. I would say that self-advocacy is like a journey and my MS has been a journey as well. I didn't wake up one day and all of a sudden become this person that self-advocated. It really took multiple steps to do that.

And one of the first things that really happened was being at a doctor's appointment and feeling uncomfortable and not understanding why. But like most people, when you get home, all of a sudden, you're just like, "Oh, I wish I'd said that” or “What was I thinking there?" And that's when I realized, wait a minute, maybe I need to speak up for myself more and maybe ask that question while I am in the doctor's office. And so that was the beginning of what I would say that I was standing up for myself and that I was using my voice to advocate. And so, once I felt more comfortable in saying, "Wait a minute, maybe I should speak up."

That's what started my journey. And that journey meant reading, speaking to people, realizing that I did have a right to speak up, a right to ask the doctors or my healthcare provider, ask them questions about what was going on with me, finding out more about my disease progression. But it also meant educating myself. And once I did that, I found that I was working with my doctor as a team and coordinating together.

So that would be a question that I would love to ask Dr. Rivas. What is it like when you have a patient who advocates for themselves? What does that look like from your perspective?

Dr. Erica Rivas

Thank you, Anita. And thank you, Yahaira and the Multiple Sclerosis Association of America for having us here and for creating this wonderful space for us to be talking about self-advocacy and particularly towards MS. So, I have a strong, I guess it's opinion, in working together with patients in making sure that we are equal counterparts to their care. And when I think or hear people, "Oh, this doctor said I have MS and gave me this group of medications to pick something from here and that's it." And it's like, that's not how we do things. At least I don't, you know, want to do something like that.

It can be overwhelming when we first received that diagnosis or if we're having progression or any new symptom, right? So, I want people to feel comfortable talking to me about what is it that they're experiencing. And I always tell my patients, "Hey, I'm not telling you what to do” right? I'm not going to tell you, take this or do that. I'm here. I might have a little bit more knowledge about some things in MS. Of course, you know your body, so you have more knowledge about that. And together, we can understand better what may be the best direction for you and make that decision together.

So, I think that's very important that you find a doctor that you can trust, that you can talk to, you can ask your questions, because they're a partner of care with you, right? There’s this paternalistic way of medicine that hopefully we don't practice that anymore, right? That's something very old. We don't want to go back to that. We want to work as a team together.

And I encourage that in patients and I know sometimes it can be hard, right? But that, to me, has been the best way that we can care for patients and patients feel also heard and helped.

Anita Williams

And so, with your perspective from both the patient standing up and advocating, asking questions, working with you as a teammate, and then also from your perspective, teammates. So, it's like working really together and collaborating.

Dr. Erica Rivas
Yeah, most definitely. Again, I think this is the more efficient way of dealing with a chronic condition, right? This is, unfortunately, a disease that is here and it’s accompanying you for life. So, we need to make sure that from the very beginning, as soon as we can, I try to find somebody that will advocate for us and will be there together with us.

“We'll accept our friends and family that want to come to the visit, right? If I don't understand something, can you explain it to me?” And so, we really want to have that relationship.

And it goes both ways, right? So, both people need to feel comfortable, and the doctors also want to- need to- be able to feel comfortable helping people with their chronic illness.

Yahaira Rivera
I have a couple of questions for Anita. Anita, was advocacy something that you naturally felt comfortable doing, or that is something that came along the way as you learn more about the condition and about advocacy?

Anita Williams
I was paid to be quiet as a child, so being really forthright was something that came naturally to me, but that's not the same thing as being in the doctor's office and standing up for yourself. It's a completely different situation where you're depending on another person who is more knowledgeable and who's a specialist with a chronic illness and a disease that you have.

And so, the self-advocacy part came with educating myself so I could bring my best self to that doctor's appointment. And that's a responsibility that I learned that I needed to do. And that's the difference between, as I said, standing up for yourself and then advocating for yourself is getting that knowledge about your disease. And then also notes on, you know, how it's affecting you, all of those things. And so, once I started doing more, that's when I felt like I was actually self-advocating.

Yahaira Rivera
Thank you, Anita, for sharing that with us. And Dr. Rivas, from the clinician's perspective, what changes when a patient feels empowered to advocate for themselves?

Dr. Erica Rivas
That's a very good question, Yahaira. When people start advocating for themselves, like you said, there's some level of empowerment and control over their health care, right? They're asking, they write questions, they're reading, they're getting educated, now they're asking questions that are more relevant, and they come prepared for their visits, right? They have all the list of questions, concerns, "What about this medication?" Sometimes I even have patients ask about drug interactions. “Would this be safe with this medication?”

So, I think that leads to a more fulfilling conversation in the office visit, at least that part. So, I encourage my patients, even at the end of the visit, I'm like, any last questions, please ask me questions. And I actually appreciate and enjoy when patients come with questions and sometimes, they're like, “I'm so sorry, I have another question.” Like, no, don't be sorry. I love helping. I love educating.

And we know different things, right? I have maybe a little bit more knowledge about MS and just that. But again, like, we're both still learning from each other, right? And there's always new things. So, we always have to be aware of what's new there. There's research, there's this medication maybe that they're looking into, right? And if I don't know it, like, let's figure it out together, right? So, this is part of advocating. And for me, being another partner in the care of this patient.

Yahaira Rivera
Thank you, Dr. Rivas. And now I'll pass it to you both so that we can continue this conversation. And let's begin with the most powerful advocacy starts with you.

Anita Williams
I think the most important thing to remember is that advocacy actually starts with you. It starts with you first recognizing that it's something that needs to be done. You're not going to be able to pass it off to someone else, and you're not going to be able to blame anyone else. It is you.

MS is on your lifelong journey with you and then that means that advocacy starts with you. And so, what does that mean? That means learning to educate yourself. Definitely go out and read. There are a lot of wonderful resources out there. Definitely start with MSAA because they absolutely provide you with significantly important information that you can trust. So, you can always start there and then branch out and begin to educate yourself.

The second thing that you can do is that you can even practice speaking up. You can write down the questions that you have, and you can even sit in front of a mirror and practice what it would be like to ask those questions and what it feels like to speak out. And actually, saying those words out loud can often make it easier so that when you go to the actual appointment, you can actually speak out.

So, the other thing to remember, too, is that even though that advocacy does start with you, and even though you need to start educating yourself, it doesn't mean that you do it alone. Doing something for yourself means you're doing it for you. It doesn't mean only you do it.

So, one of the most important things that you can do, and this is something that I found to be the most difficult thing to do, please, hear me when I tell you, ask for help. There is nothing wrong with saying to someone, I need you to assist me with A or B or C. It took me years, literally years, to actually be able to say to people, I can't do this by myself. And I hope that anyone who is newly diagnosed or anyone who was oldly diagnosed, please reach out to other people and let them know you need help.

It's not weakness, it's actually strength to be able to look at someone and say that there's some place where you may feel weak and that you need help. But asking for help is never, never, never weakness. So please know that if I can give you anything, please ask for help. Do your part that you can do but absolutely know that others can help you.

Now, that also leads into that question of family and friends and what that is like when you have multiple sclerosis and how advocacy works in a different way, which is with your family and your friends and that relationship. Advocating for yourself is not just for something you do at your doctor's office and your appointments. That means looking at your family and friends and also being able to do things like setting boundaries.

Setting boundaries means that you can say to them, "These things are okay and these things are not okay." And that has to do with protecting yourself, protecting your mental health, protecting your physical health. What does setting a boundary mean? Setting a boundary might mean telling people that you can't text me or call me after six o'clock in the evening because maybe it takes you two hours to settle in to go to bed. And that even though it may sound like it's really early to people, that's okay. That's your boundary. So, it's okay to tell people that there are things that are acceptable to you and things that are not.

The other thing though about self-advocacy that I think is also important besides setting boundaries are kind of the opposite of that. It’s being able, again, to go to people and to ask them for help and for favors. And it might be something as simple as, "Hi, you know, when I get to this, can you pull this chair out for me?" Or "Can you make sure that the aisles or the spaces between tables are big enough for my wheelchair to fit through?" Or for going to a movie theater, make sure that there is handicapped or disabled seating available so that you can participate in those things.

That's also part of what it means to advocate for yourself with friends and family. It's the same thing you would do in the doctor's office. And you may have questions for them, such as, can you do A, B, or C, or can you not do D, E, F? So, it's important to be able to do those things with your friends and with your family.

Yahaira Rivera

Thank you, Anita, for sharing that candid perspective with us and all the examples that you shared. We received questions about how to establish healthy boundaries with family and friends, so we appreciate your feedback on that. And now let's talk about advocacy at work. This is another context, but sometimes it's hard to advocate at the workplace.

Dr. Rivas, can you give us some information and insights about how can someone advocate at the workplace?

Dr. Erica Rivas

So, this can be very challenging, right? Because people might feel more comfortable with themselves, with their friends, close friends and family. And they might feel that if they disclose diagnosis or symptoms or they speak up, there might be repercussions, right? And they might feel guilty, or they might feel that maybe they're not going to be taken seriously. So, this is certainly the next level of challenge, right? So, once you learn, okay, I can advocate for myself, and I have the family and close friends that understand me and know me well and they will advocate for me.

Now how do we take that to the work where you're dealing with some colleagues and your boss and maybe people that you may or may not be as close. So, that's a challenge on its own, right? But if we can overcome some of these challenges. It's like it might be easier when people have some visible symptoms, right? Or other people might approach you and say, "Hey, I noticed that you're having a limp. Are you doing okay?" Or "I noticed that you have a face like you may be in pain or discomfort," right?

So, that could be perhaps a little bit easier for patients to, or people to come up and say, “Yes, I have been dealing with some, health issues” or, you don't have to fully disclose what's going on. And so that's one thing, right? And then the other challenge is invisible symptoms where it would be harder for other people to perceive that you're having brain fog, or your thoughts are a little bit cloudy, or that you're trying to do an inventory and you like have to go back again and do that and spend more time to ensure that, or a task that, you know, it took you half the time and maybe people are starting to notice.

And then that can bring self-doubt and stigma or any doubts about your ability, right, to be a productive employee. So, as much confidence that you have or how comfortable you feel in bringing this to your employer, you can disclose as much or as little as you want. If you're needing accommodations at work, that's one thing that you can discuss with your doctor. You know, "Hey, I'm noticing that I'm having more trouble. It takes me more time to check this inventory or balance the sheets or I'm having to take more bathroom breaks and like my office is super far.”

So, how do I talk to my boss or my employer about those accommodations? If there is an HR department or a supervisor, that would be the people to talk to about getting accommodations. And sometimes they will say, "Okay, yes, you can take this form to your doctor. They can fill it out. We might need to get records," et cetera. And again, you can disclose as much or as little as you want about what's going on with your health. But if you need accommodations, I think this is also part of self-advocacy, right? I just speak up like, "Hey, I need to be closer to a restroom" or "I need more time to finish this." And your doctor should be able to help provide any documentation needed.

And I've had it done where like, okay, I filled this form. This is another form that looks just the same, but let's just send it again. And that's on us, right, to really try to help you so you can get those accommodations. If you need more breaks, if we can anticipate that maybe, you need to stay home for half a day every so often, right? So those are things that we can help accommodate.

And if that's in place, it's actually, easier for the employer, right? They know that, okay, there's going to be some times where you're going to be out or that we might need more help. So, they can organize themselves too. And then you can get the breaks that you need, for example.

Anita Williams

And interestingly enough, that actually leads into the community. And one of the things that really struck me was forms. And there are times where you might need to ask your healthcare provider to fill out a form such as for a handicap placard for your vehicle. That's something that people sometimes don't really think about, which is yes, if you have difficulty with mobility - and it doesn't have to be consistent mobility. It can be, for instance, if you have issues with foot drag off and on and you're not sure, definitely get something like your handicapped placard that you can use either consistently or if you just need it every once in a while.

And so, with that comes the idea that when you're in your community, you might want to let people know that you need to park closer to, sometimes, the different events that are going on, and that do they have those things available? Speak to the community about issues accessing going upstairs. Are there elevators available? Those are things that you might find, but make sure letting the community recognize that, “Hey, we have access issues that are going on” or

things that have to do... I have spasticity in my arms, and so things like actually having the buttons to push for the doors to open, absolutely worked for me.
So those are other ADA things that you also may want to speak up about and make sure that things are, and places are compliant with those sorts of things. Now, if you're also looking at your own personal community, that also goes back to with what Dr. Rivas was talking about, which was whether or not you want to disclose. Just as you may decide that you do or don't want to disclose to your work situation, you can also have the choice to disclose whether it is to a church or to a mosque or to wherever you're going. Is that something that you want to share with that community? You don't have to.

It is absolutely your choice who you want to let know that you have multiple sclerosis. It is not a given that because you are a part of a community that has been supportive of you in the past, that doesn't mean that you owe them information about what is going on with you. So please use that same discretion that you would use with your family, friends, and work, with the community. You can share or not. So please don't feel pressured to think that "Well, this is, the people are wonderful and other people have shared, and so there's this pressure." No, there isn't.

But remember, again, that these are people that can support you. So again, like with self-advocacy, it's up to you to choose what you want to share, what you don't want to share. So don't feel as if you need to tell everyone or that you need to hide. Definitely up to you.

Yahaira Rivera
Thank you for that, Anita. I think that was very powerful. You know, being honest, but also having grace with yourself and it's up to you, it starts with you. If you need the help and you feel comfortable sharing about your diagnosis and sharing about your needs, that's amazing and that's powerful and there are ways of doing that.

But even if you feel like you don't feel comfortable disclosing, there are ways of asking for help without giving so many details. So, I love that it's a very unique situation, but like you said, it's up to you. And there are ways of doing advocacy and taking it to action in different contexts and settings.

So now we're going to switch to, as someone who's living with the chronic illness like MS, and you are a patient, how do you prepare for appointments? Appointments sometimes get very little limited time, right? 15 minutes, 20 minutes, depending on the purpose of the appointment, depending on how busy the clinician is. So, this is very important to maximize that time.

So, I will pass it over to you both. How can someone prepare for appointments and during that time, maximize the visit, but also practice self-advocacy?

Anita Williams
That's a great question. There's always a point where you have to recognize, as you said, that your appointment is limited. And that means you need to prioritize what it is that you want to talk about. And in prioritizing, that comes with the self-advocacy where you are paying attention to your symptoms on a regular basis.

And thinking about regularly, what's important to me? What's important to you might be if you feel as if something's progressing. Perhaps you have, I have trigeminal neuralgia, which is a very weird, sparky jaw thing. And if I feel like, wow, you know, I'm getting a little bit, this happening more often, that's something that you may want to put on the list as this is most important because it's happening more often. Or are you noticing that you have something new? Are you having maybe your fingers or your toes and feet are tingling all of a sudden? That's something you may want to put on your list.

So, what I would recommend doing is paying attention to what's happening to you on a regular basis and keeping notes of that. And then once you keep track, you can look at that sheet and you can actually say to yourself, "You know what? What on here is the thing that is worrying me or bothering me the most? What is that thing that I think about when I lay my head down at night or when I wake up in the morning?”

That's one way to prioritize what it is that you want to talk about. Once you decide what you want to talk about, that's where the questions are important. So, if what you want to talk about is that your fingers are tingling, then the question isn't just “My fingers are tingling.” It might be “My fingers are tingling at this time. What do you think might be causing that to happen?”

So, once you identify what's important, that's when you start writing the questions that you want to ask about that during that time when you are thinking about "What do I want to take with me?" So, definitely have those things prepared, but also most importantly, recognize that you need to be efficient with what it is that you want to ask. So, questions that are specific and questions that are shorter, I think, are the ones that are going to help you the most.

So, Dr. Rivas, for you, when someone is coming in for an appointment, what would you like to see? What helps you help them?

Dr. Erica Rivas

Well, I think it's important, right? So, you keep track of some of these symptoms and if we often ask, “Okay, when did the symptoms start and how long has it been present for? Is it always there? Does it come and go? What things make it better? What things make it worse? Is there any pattern? Have you had that before or not? Could this be a pseudo relapse, right? Or is it a completely new symptom? And does it interfere with your day-to-day? Or have you tried any medications, or have you tried any therapy? And has that been helpful?”

So, I think, you know, and this is also something that you will learn as you... having this established relationship with your doctors and okay, yeah, these sort of questions that they ask. So, when you're taking notes, then you know to look for those answers, right, or that you might have to share with the physician. So, that's part of, tracking, tracking your symptoms and it will help us kind of try to understand, what's the priority to this? And is this something that's MS related or not MS related?

So, and again, it's a whole learning process, right? So, it takes time to be able to understand what are the relevant questions and things. And if you don't even know, is this going to be relevant or not, but it's in your mind, just ask or write it down, right? So, I think that's going to be important understanding that. And another thing. Then you mentioned, are we having new symptoms, right? That's a moment where you would pick up the phone or send a message.

Any new symptom, that's something that needs to be addressed as soon as possible. Because if it's a new relapse, you want to take action then and there. We need to put that fire out. So do not wait till your three-month appointment. "Oh yeah, this happened three months ago. I got numb or weak on this side and just waited till today." Right? Those are moments that we're like, “No, please call us or message us. Let us know that there's been a change.” And that is significant.

So, we would want to know that ahead of your visit, right? That's set up. That's again part of advocating for yourself. But, and then there's times that- there's people that are- better at explaining things. And I'm talking from a provider side, right? We can, we use big words or we use words that everybody can understand, right? So that's for us, right? That we need to be able to convey information in a way that anybody could understand.

So, it takes practice, right? And then talking to people, and for us not to get frustrated if they're asking the question again, or can you try to, “I can't understand it, can you ask me, can you explain it to me in any other way?” So, we should be able to help with that. Like, okay, let me rephrase it this way. But we wouldn't know if you don't tell us, "I'm not understanding," or "What is it that you say, or what is that word that you use?"

And in practice, I tend to avoid, you know, any medical terminology, right? And even if the other, you know, person is in healthcare, or a healthcare worker, I still like to keep things simple where everybody could understand.

You know, the other thing here, which is the interpreter right so it's... in my case I'm bilingual in English and Spanish. And I see patients in English, Spanish. And then there's times that the patient themselves, they might prefer Spanish but then the family member might prefer a different language. In fact, I have a patient that she's bilingual English and Spanish and the mom is primarily Spanish-speaking so we do cover the visit mostly in Spanish, but then with the patient, sometimes I say things in English and I might look to the mom and translate some things and she's like, “Yeah, I understand.”

So, it's just also being aware, right? And reading the body language and are we having a meaningful conversation? And if it's not English or Spanish, we have a service and we can put Vietnamese and whatever language, but we want to make sure that we convey that information to the patient and their family and friends that came with them to the visit. So that's absolutely important that we communicate with each other.

Anita Williams
And just to go back, thank you so much for talking about new symptoms and that they need to be reported immediately. I really greatly appreciate that correction. That's the kind of thing that we keep learning as time goes on and so I'm really glad that you brought that up. And then also, at the very beginning, you had a wonderful list of questions that we should be asking, which would be more specific about the particular symptoms. So, I would say that if you're watching the webinar, I would roll it back to the very beginning of Dr. Rivas's answer, because I just think it was absolutely brilliant, the list of questions that we're talking about because those are exactly the kinds of things that we, as self-advocates, should be bringing to the table when we show up at that appointment.

So, I would say pause, roll it back, and write down those questions because they're absolutely wonderful and an example of what self-advocacy looks like when you're sitting actually in the healthcare provider's office.

Yahaira Rivera
Thank you so much. This is such a crucial part of self-advocacy, right? Preparing for appointments, but also what to do during the appointment, how to have those conversations with the provider. And Anita, you're right, these questions, the question stems always help to

have that focused conversation, to not lose track of what you wanted to share with the provider.

And we have some examples here. When you're looking for clarification, can you explain that another way? Speak about what matters most to you. For example, Dr. Rivas, “My goal today is to improve my quality of life on this aspect of my life,” or what have you.

Confirm next steps. I think that's very important. What's the plan? What's the next step? And something that Dr. Rivas mentioned, too, for example, when reporting new symptoms. It's important to know what is the mechanism of communication between appointments. I know some for providers, they use like a messenger, like a portal, right? Like a messenger system for the patients to send messages to the nurse practitioner or to the staff or directly to the provider. Sometimes you have to call them. So, it's good to know what is the system in place, how to leave a message, how to, if it's an emergency, who to contact.

So, all of those are details that are important to keep in mind. And something that caught my attention is, you know, a lot of providers that we work with, they usually recommend to bring a second pair of ears, a friend, a family member, just because maybe you get anxious about the visit or you are thinking about other things during the visit and you can miss important details.

What about people who are not able to bring a friend or a family member? What would you recommend so that they can take notes, or have a list of questions or write down next steps? What would you recommend to people that... maybe their support system just looks different?

Anita Williams
From that perspective, you can always ask your provider if they would mind if you record your visit, and you can make that a voice memo, and then you can record what they're saying, and you can listen back to that later. So that's absolutely one option. Another option is to, if the family member's available, but not to be with you physically, you can also call them on the phone and have them listening to everything that's taking place during that call and to be able to take notes for you.

So those are a couple of options if you don't have a family member that's going to be physically present with you. So being able to, again, record or to have someone on the phone or on a video call at the time that you're doing your appointment are two other ways that you can take care of that if you are someone that doesn't have immediate support.

Dr. Erica Rivas
And from my perspective, I would say that, if you try to focus on the conversation, it's hard. I think our brain is still developed to listen and take notes and do all this multitasking, right? So, I think just trying to pay attention is the best thing you can do. And at the end of the visit, you can ask your doctor or your provider, hey, can you summarize what we talk or what are the things that I need to do, right, or pay attention to? And at the same, the counterpart, right, I can ask the patient, “What did you understand from all this? What are the things that you need to do? What are we doing?” So, just so I can make sure that they understood the conversation. So that's another way of making sure that we're all on the same page.

And then now there's AI, right? So, AI can help and use it to help transcribe the notes so people can, they need the notes, right? So, it's easier for me to say, “Okay, let me just sign this and you can take the notes.” Or we can have an after-visit summary. And these are the points that I talk. And sometimes I write it down for them if they need that. And if they need the note and there's, I've had patients also like, "Oh, I'm gonna have my, you know, son that lives in the UK join," I'm like, “Okay, welcome,” right? So, the more the merrier, and I welcome questions, and it's a good conversation when we have everybody engaged.

Yahaira Rivera
Thank you both. Those are great ideas and great advice, and we appreciate the examples that are realistic, and our community members, I'm sure they can go back and apply it right away, so we appreciate that. So now moving forward, let's talk about finding the right provider, because this is important when someone is living with MS and the shared decision making, and having that trust in that relationship.

So, Dr. Rivas, can you guide us in this conversation about finding the right provider and what to do when that's not the case?

Dr. Erica Rivas
Yeah, so I tell my patients, this is like you're dating, right? So, if this doesn't work out, it's okay, we can break up. There are no hard feelings, you need to find somebody that understands you, and vice versa, right? So, there's nothing bad in like feeling whatever, like you didn't like the bedside manner, so you didn't connect, or whatever it is that you're feeling. And you can move on to somebody else.

So, you need to find somebody that works for you, that shares your values, your goals, that communicates well. And then, personality is another thing. I have people say, "That doctor was smart, they know. But I just didn't like their bedside manner." And that's okay. You need to feel comfortable, again, particularly with dealing with a chronic illness.

You need somebody that's going to be with you for a very long time, just by your side. Walking the journey with you. And that can take you seriously, understands your concerns, that you can understand the explanations, right? And then that we're respectful with each other. It goes both ways. And in that we are a team when it comes about the care management.

So, we're a team and this is, we call it shared decision making. So, culture, language, identity. That is who we are and what makes us unique. And I think that's important that your doctor also respects that, or your healthcare provider. Not only the doctor, but everybody in the team, like the nurses, you see a nurse practitioner, right? That they respect you for who you are, and that they take you seriously.

Part of the reason also why I'm doing what I do, and where I'm at, is because I want to spend time with my patients, especially when we talk about MS. There's so many aspects to MS. It's not just, you know, I have this one symptom. It can be anything, right? And everything could be MS.

So, we have to really spend the time, ask the right questions, to try to figure out, okay, is this MS related or not, or is this neurological or not, right? And then how do we address that? So, I like to spend ample time with my patients, make sure that I answer older questions, and that they have a care plan. "Okay, this is going on, we're gonna do this. And then this, for this other thing, we're gonna do this." So, there is transparency within our communication.

And those are some green flags, right? Things that can tell you, "Okay, maybe this is the good thing here that we're creating." And then what are your red flags, right? So, the day, could you not understand them regardless if they were nice or not? Was there any communication issues there? Did you feel rushed? Did you feel that maybe they didn't pay attention to you or they didn't take you seriously? So those are some red flags that you're like, "Well, maybe, you know, this is time for me to move on and find somebody else, get a second opinion."

And it's okay. Even my patients. If they, you know, like, if you want a second opinion, that's totally okay. I'd rather have somebody else to tell us, “Okay, this is our opinion, this is what I'm thinking.” Because yeah, again, I don't know everything, right? And somebody might see something with a different perspective. And then, okay, that makes sense.

So, for me, there's no hard feelings. I don't feel betrayed. Like somebody wants to see something. Yeah, perfect. Let's do that. And then tell me what did you think and what's going on. And there's times that people have their local neurologist and they're like, “You know, I feel comfortable. They're right around the corner, but they're not an MS expert.”

I'm like, fine, you can keep your neurologist, see me maybe once a year and then we can both work together. You don't have to choose one neurologist even or one doctor necessarily.

Anita Williams
And I love what you said about not having your feelings hurt. I think that's one of the things as a patient, when you want to switch, is you're often really concerned about your doctor and is my doctor going to be upset with me? Are their feelings hurt? And it's great to hear you say, no, I don't take it personally. Because that can free a lot of people from a sense of guilt or feeling like they have to be with someone that they're not comfortable with.

And from my perspective, I have changed neurologists a couple of times. One of them was, as you mentioned, I just didn't feel like it was a comfortable fit. I couldn't still tell you, but there was just something in my gut that said I don't know what it is. Perfectly wonderful, wonderful person, but we just didn't seem to be on the same page or in the same book. Wonderful person, very, very charismatic, very skilled, but it just didn't feel right.

And then the other one was a different one, which I think we all seem to pay attention to is the very first thing that this new neurologist asked me, was whether or not I had considered a gastric bypass. And when I said no, it was "Why?" Now, that was the very first question that was asked. It wasn't anything about my multiple sclerosis. It wasn't really an introduction. It wasn't trying to feel out the potential relationship.

And so, at that point, I was like, "No, I don't want to deal with this person." But the thing about it is this, that before I learned to advocate for myself, I would have probably listened to this neurologist and said, "Wow, you know, he's right. I am really fat, and so I really should not take what he said personally, and what he said was right, and I probably should think about a gastric bypass."

That would have been the old me, that would have listened to what it was that they said. But the newer me that was proactive and that was doing self-advocacy said, "No, I want to discuss what's going on with my multiple sclerosis first. I'm a person. I'm not a visual cue. I'm here to talk about multiple sclerosis, which is your specialty. not gastric bypass." And so, in that situation, I felt a right to change neurologists, even though it is clear that I do have an issue with weight, and it would help me, for me personally, it would help me medically to take some pounds off.

However, the feelings that society may have had on me, or any guilt that was put on me about my weight, self-advocacy stopped that guilt and that shame from society and said to me in my head, "Wait a minute, you're here to see a neurologist about multiple sclerosis, which is the chronic illness that you're carrying for the rest of your life." It's okay to say, “I don't want to have this person as my provider. Even though what they have to say may be true, it's okay for me to say, no, I want someone else who's going to deal with my multiple sclerosis.”

So, in both of those situations, it was the self-advocacy in me that said, you know, this isn't comfortable and it's okay for me to go with my gut. And then the second situation for me to say, that might be true, but that's not what I want for my primary care provider for my multiple sclerosis. And so, in those situations, that's where self-advocacy comes from, by looking at yourself and using your own feelings and your own internal voice to say, I can bring somebody else along with me.

Because again, we talk about MS as a journey and your multiple sclerosis healthcare provider, that MS person, is like a persistent hitchhiker. You know, you're going to see them at exit 36 and they're going to ride along with you to your meetings until you get to exit 38. And you're going to motor along and motor along and motor along, and all of a sudden, you're at exit 60. Hey, there's that hitchhiker I saw before. Hey, jump on in.

And so, the fact is that do you want this person next to you for a few exits? You know, is this somebody you want to listen to music with, share some snacks? Or is this somebody that you're like, I think I'm going to bypass that person?

So that's what you can do with your provider or somebody that you feel comfortable as a teammate and working with them. And this is probably the few times in your life where you get to choose the person that you're working with as a team to help you get better.

So, I definitely appreciate what Dr. Rivas said about not feeling like you're going to hurt your physician's feelings. So, forget about that and think about, who do I want to have sitting next to me riding shotgun?

Dr. Erica Rivas
Absolutely.

Yahaira Rivera
Thank you both. Thank you, Dr. Rivas, for sharing your perspective as a clinician and thank you, Anita, for being so open and transparent and sharing your experience and your journey with us.

So now, speaking about the healthcare setting, when individuals living with MS go to an appointment, whether that is with their MS specialist or with other clinicians, let's talk about how can they advocate in these settings, especially when they feel that they're not being heard or understood.

Dr. Erica Rivas
So, I typically like to ask my patients, especially your first time we're meeting, “What's your goal with this visit or this consultation, how can I help you?” Because some people might come for, "I just wanted or need a second opinion" or "I want to transfer care. I'm unhappy with my prior neurologist." Or, just whatever the reason is, I want to make sure that I understand why

they're there, what's their objective, what's their goal to that visit, and then we can kind of continue on the conversation.

So, I think that, when I hear, "Oh, this is my biggest issue," or "This is my big question or my concern, and this is what I want to get out of this visit or your opinion," I think that helps me focus and help answer their main questions that they have.

So, I guess that that's the one sentence summary, right? Start with, why are we here? What is our goal? And then it helps us if you bring a list of your short symptoms, or just a list of your symptoms, or if you rank them in order of priority. Because like we said before, unfortunately, our healthcare system is limiting more and more and more the time that a healthcare provider is with you. So, you want to make sure that the things that are the most concerning, at least you get some answers or clarification on those.

And if it's symptoms, just make sure that you bring a list of those symptoms. And again, as you continue to learn more about the questions that we ask, “So when did it start” and all that, right? “What makes it worse?” So, there's a little example here of what we said before. So, you have that as well in your list there. We ask, what are the next steps or where we go from here and if we need clarifications. So “Can you explain this to me again?” Or “I just didn't get it the way that you said it.” Or “Let me think about it, let me discuss this with my significant other.” Or “Can you make sure that you put this on my chart” or “You don't put that on my chart.”

Sometimes people feel comfortable outside of the paper, right? Like, “Hey, I'm going to tell you this, but I don't want that to be in there.” So, we have to be receptive of that too. Don't be afraid to speak up if something is not working in a respectable way. Again, both ways. We can disagree and still be respectful with each other.

It's like, “Hey, you know, I don't think this is working for me. Can we try something else?” And we can definitely talk. If you can bring support when possible, we're saying a friend, family, even in person or on the phone, that can help take notes and also advocate for yourself by asking questions or “What can I do to help my significant other or, my, person that I love, that I'm here with.”

And then, you can use notes in your phone or writing things. And then again, making sure that we communicate in your language, or the best possible way. The other thing more for the physicians is sometimes, we're in this kind of rush and you just want to get to the point. But we have to let patients talk, right? They will eventually get to the point if that's what you're concerned about. Sometimes they might have cognitive issues, or brain fog or a speech issue, that they might have some struggles in communicating what they need to say.

So, we need to be patient too and allow safe, ample time for people to express themselves and, in either a language issue or communication, more of an articulation issue, we need to respect that as well.

Anita Williams
What I really picked up on and really liked was when you talked about the goal. And it's one thing, obviously, to come forward with issues that we have, perhaps symptoms, things of that nature. But beyond listing those things that are going on, the other thing we have to think about is what is the point of bringing those things up?

It can't simply be to go to your healthcare provider and say, "I have all of these symptoms. Now what?" That's not fair to you and it's not fair to them. It's not fair for you to bring symptoms to them and then just lay it there and then make them try to figure out what it is.

So, if, for instance, I have spasticity in my arms as opposed to my legs. And so, when I bring that to my healthcare provider, I can say, “Hey, I have all these things. My arms are locking, my arms are sore,” all of these issues, and then... and what? When I bring those issues, it would be “My arms are locking. I'm having issues with pain. I would like to find a way to eliminate those issues or a way to make it work, make them work better.” And that's, again, that's where that teamwork comes in.

So not only am I coming with a list of symptoms, I'm coming with what? My goal? My goal is to, obviously, hopefully they don't hurt as much, or how do we help with them locking? And then that's where you have that conversation. And sometimes the goal might be something that's going to relieve your symptoms, because clearly there's no cure for MS.

And often what we're talking about is symptom management. So, I can go and say, “The goal is to prevent locking,” or “Is there a way to make them lock less?” And then that's also where, when Dr. Rivas talked about the disagreement part. And that's essential because I may come to my physician and say, “My arms are sore, they're locking a lot. Can we just increase my baclofen so that I'm taking 100 milligrams a day? Because I think that that's what it should be.”

However, my doctor might go, "Hey, let's not just jump way over the fence. I think that we should increase it to X amount and see how it works first." And then that's, again, where that teamwork comes in, where I need to be open to what my doctor is saying, even though it's not what I may want to hear. And so that's extremely important as well, is that self-advocacy doesn't mean telling your healthcare provider what they're going to do. You know, we're not going into that area where I want what I want, when I want, because I read something somewhere. That's not self-advocacy in any way. That's not what self-advocacy means.

It means educating yourself and then working with your healthcare provider and working as a team and letting your voice be heard, not letting your voice be the only voice. It's to be heard and to be shared. And I think that's important. And again, having that goal of what would you like to happen with what you're bringing up. And that's where your healthcare provider is going to say, perhaps, "The goal that you have may not be, it may not be a goal that can happen." So, I'm told, you know, "With your arms locking, it is a symptom that you're always going to have, and we can do some things to help. but it's not going to be eliminated." And so, the goal then would be, well, how can I live the best quality life that I can with the symptom that I have from there?

Dr. Erica Rivas

Anita, I truly admire the way that you speak to others, and this is truly a self-representation of self-advocacy. Thank you for sharing that.

Anita Williams

And I really greatly appreciate you sharing your perspective as a healthcare provider, because we rarely see things from your perspective. And being able to learn from you has, I've learned tremendously from listening to you today about ways that I can be a better patient but also understand what it's like and how you feel, because you're obviously a person as well.

And that's something we also definitely need to consider and not forget that again, you know, we're a team, but you're a person as well.

Yahaira Rivera
And Anita, that was, your statement right now, you know, amplifying your voice and advocating for yourself, but also keeping in mind that there is that mutual respect between the patient and the clinician is so important and that it goes both ways.

Now let's move on to navigating insurance, denials, and the system. And this is a topic that could be controversial and sometimes it's a little bit intimidating to navigate. So, Dr. Rivas, could you give us some advice and insights on what to do if someone, for whatever reason, gets a denial to cover for treatment or for appointments, how can we navigate these in a way that is still part of self-advocacy?

Dr. Erica Rivas
Insurance is something that keeps getting more complicated and more complicated. I think that less people understand this, but getting a denial is not necessarily the end of the road here. We could do an appeal, we could do a second appeal, and even at that point, if you get denied again, there are other ways of trying to get the... let's say, if we're talking about an MS medication that you spend all the time and effort talking with your doctor, you make a decision, “Okay, this is the best drug for me based on X, Y, and Z that we discuss,” and then still your insurance denies that, we could go and get, you know, free drug from, the pharmaceutical company.

There's community organizations that can help pay for part of it, or some of it, or the treatment, for a year or six months. Same with imaging that we could get MRIs. And so, there are some resources and I learned about these even from some patients. So, there's, "Did you know that there is this website that you can get the MRI at a cost?" Like, “Okay, like what is it?” And I'm looking at it, and now I recommend that to some other people, right? So, it's not the end of the road.

It is frustrating for sure. I can't imagine for you, and then for the physicians as well, but it's not the end. It's not the end of the road here. So, we could help, right? And if not, there's ways that we could try to make it happen.

So, the other thing. If you have the opportunity to choose your insurance, sometimes they will block certain drugs or category drugs. Or if you have a doctor already, and you might want to check is that doctor is in network or not. So those are other things related to insurance that you can make sure, if you have the opportunity, to check on that or choose on that.

Anita Williams
So absolutely, I would definitely second that. Please don't let insurance be the end of the road for you. Again, there are options available and take that self-advocacy and think of it as if it's a bump in the road. It's another obstacle, kind of a fight, that you have to go through to do that.

But again, it's, you know, you're doing it. You're doing it for yourself, but one of the things you can do is think about it as if you're doing it for someone else. Think about, take yourself out of it and maybe think about, “I'm not doing it for me, but maybe I'm doing this for my grandfather,” or “This is something I would do for my best friend.”

So just, you know, don't let insurance and issues with insurance just be... okay, throw my hands up. I have an insurance problem. As Dr. Rivas said, there are so many resources available for you. There are things that you can look up for yourself, but you can also ask your healthcare provider because they may have information or access to resources that you yourself had not thought of. So just don't let it get in the way.

Yahaira Rivera
Thank you so much once again. And for us at MSAA, education is such a powerful tool. Education is something that no one can take away from you. So, I'm a firm believer that when you have access to information, you're able to find resources. You're able to not let the fear get in the way. You feel empowered to ask questions, to find resources, and to navigate the system.

With that said, do you have any insights, feedback, ideas, and suggestions on how an individual living with MS can get education, trusted resources, and how would that help them in the journey with self-advocacy?

Anita Williams
I would again say one of the first places and a wonderful place to go is MSAA website, because again, the information there is from a trusted resource. And often as a person living with MS, you have people giving you advice. It's people that are genuinely well-meaning, but they don't understand the disease, and they don't understand how you are personally experiencing the MS. And even if you have the same symptoms as someone else, it's not always going to be expressed in the same way because everyone with MS is absolutely different.

And so, I would definitely stick with some of the bigger organizations that are there. Obviously, you have MSAA and the National Multiple Sclerosis Society. That's also a great resource. And so, I would, come to go with the big two on that one because they both have information. And again, the most important part of that is making sure that the information you're getting is from a trusted reliable resource.

So those are the two sources that you absolutely cannot go wrong, starting with them. Because from there, they will make sure that the links that you're getting are going to proper organizations up and down, you know, the multiple sclerosis stream. So that is absolutely where I would start. And then you can branch out but always be careful of what you're looking at and if you are in the forums and people are sharing their information, absolutely, forums are great for support. They're great for finding information, but don't simply take what someone has written or something that you read. Don't take it as kind of the gospel. Make sure that you toss that information into Google to start and then go from there.

Yahaira Rivera
Thank you so much, Anita. And I, of course, piggyback with you what you just said. Use trusted resources. MSAA is here. We provide a plethora of publications, educational materials, we have webinars, not just about multiple sclerosis symptom management, but we have digital tools and other resources to help you navigate the MS experience and different topics to learn about, and from.

And Dr. Rivas, would you like to add anything about the importance of educating ourselves and finding community support?

Dr. Erica Rivas

I agree with what Anita said. So, trust but verify is like the other motto that I tell myself and patients. "Okay, so we're hearing this" and "Where is the source of this information?" And yeah, I mean, Google is just internet, right? It's a big sea of information. Whether that's accurate or not, now it's our job and your job to figure that out.

So, credible sources. These are national organizations that they're vested in educating the community, so, absolutely. And then, I tell my patients, if you see a big hospital system, like John Hopkins, Harvard, Cleveland Clinic, you can go to those pages and read about MS and the resources there. I would be cautious about the articles or some magazine that's not MS related. Sometimes people can post some article, and you don't know the validity of that article necessarily.

And then for the scholars. If you understand scientific journals, there's a PubMed, for example, where you can read the research on some topic if you have that level of education, if you're a scholar. So, that would be sometimes hard to interpret, even for somebody that's, maybe a scientist can sometimes even be a lot, especially if you're talking about the basic science of MS, which it can be a little bit daunting.

But yeah, I think reading something and making sure that, is this accurate? If you have any questions, ask your doctor, “Is this accurate?” And then we could help navigate that with you as well.

Anita Williams

And the other thing, I had mentioned Google quite a bit, a bigger issue also is AI. And people love ChatGPT or Claude. And while those can be really great sources of information and can help you understand things, they're not a replacement for the knowledge and information that your clinician has for you.

So, your healthcare provider knows more about your background, your history, whatever issues you're having, the medications you're taking, you know, all of those things. And so, AI is not going to be replacing your healthcare provider anytime soon. And while it can be a helpful resource, don't take that as being the end all be all. And then say, well, ChatGPT says, you know, this particular thing, you know, you can take that with maybe, a larger grain of salt.

And there are things that can be helpful, but please don't think that AI is going to be the absolute answer to every question that you have about multiple sclerosis, about your symptoms, about chronic illness, about all of those things. Your healthcare provider is still there and has answers to a lot of your questions that you have about what's going on with you clinically.

Yahaira Rivera

Thank you both. Absolutely. So, finding reliable sources like MSAA and other national organizations, and when in doubt, always check the sources. And also, I think going back to the community support through our organization and other organizations out there, and also your clinic, the local clinic, your provider, ask about where is a good source to find information about MS and other related topics.

Another important part of advocacy is engaging in clinical trials, engaging in participating, whether it's an educational program, attending an in-person program, joining a webinar, but also participating in clinical trials, which is sometimes controversial and sometimes people are afraid of because of valid reasons. But can you give us some advice in regards of participating in clinical trials and why representation in clinical trials matter?

Anita Williams
Yes, I am a huge advocate for participating in clinical trials, particularly for communities that have been overlooked in the past and that have been mistreated. And that's one of the main, that's actually one of the main reasons why I have done clinical trials and participated in research is because there is a lack of information about how multiple sclerosis affects women of color. And as time has gone on, we have found that more black or African American women have multiple sclerosis than they had thought previously.

And so, what's important for me in participating is providing more information to help other women now and down the road. And so that's why I feel this pull and need to participate, because I stand on the shoulders of the people who participated in clinical trials. And that's the reason why, when I was diagnosed 11 years ago, why they were able to say to me, "Here are your options for multiple sclerosis drugs." I had infusion options. I had options for self-injection. I had options for whether or not I wanted to take a pill. All of those were available because people before me decided to participate in a clinical trial.

And so, I wanted to pay it forward by doing that myself. And I know that there are questions about whether or not they're safe. And the fact is that clinical trials have come a very long way since even the 1970s. The safety protocols that are put in there, the influence that people participating as patients have, that was not available before. So, our voices are heard from the very beginning to other parts, you know, down the road during the research, the different segments, our voices are being solicited and being heard.

And so that's why I say that our participation is absolutely essential because that's what's going to help move along the progress that we've been making. So that's where my heart lies when it comes to multiple sclerosis and my participation. It's absolutely with science and with research. And I would absolutely recommend that people participate. And if you have any questions about it, just do some research and find out a little bit more for yourself about what it is.

And I know that there's an organization, iConquerMS, that is dedicated specifically to research and to the patient and people-centered part of research so that it's not this cold clinical, "We're just going to take something from you and not give back." It's a completely different situation. And I think learning more about it would absolutely assuage or make you feel better about any of the fears that you may have had in the past. So, I really genuinely recommend that and ask and really ask that you consider participating in clinical research or any other kind of research.

And I know obviously for Dr. Rivas that clinical research participation would obviously be something that she would like to see her patients participate in, I'm sure.

Dr. Erica Rivas
And I can understand the hesitation in some people, right, especially with our history, right, with research, right, and how is then, how it is now, how it will be in the future. And I hope that things continue to improve for the safety of everyone. But yeah, there's historically some safety concerns, right, when we were studying, doing research, or studying drugs or certain diseases.

And we've come a long way where the safety of the participants is the number one priority. And after that, we want to make sure that people are informed about what is it that our objective is with this clinical trial, what's the question that we're trying to answer, what are the benefits to you, what are the benefits to the medical community, what are the risks to you, and that we list everything because, of course, there's benefits to everything and there are risks to everything.

And I tell my patients, "If you need to cross the street to get to the store, you have to do that." Like, what's the benefit? You'll get to the point that you need to get, get your groceries, but you have to cross the street. So, you have to be careful, informed. So, you can make the best decision for yourself when you are well informed. And there are a number of different trials, whether it's trying a new medication, something novel, or just filling out a questionnaire, or even post what we call the real-life studies.

So, they approve a medication and now we want to know what is happening in their real life, because when we do clinical trials, these are participants that are very rigorously selected. They have to be a certain age, they cannot have other medical conditions, they cannot be on this medication. So, it's very selective, but how does that translate in their real life? Where this is a medication that's already approved, let's say, and then we use it for the treatment of MS.

Now we want to understand how it is affecting everyone. Different genders, different races, and you have different medical comorbidities. So that's important for us also to understand real life, right? And then we're not necessarily treating or giving you something, we're just collecting information and that's de-identified information. So, in any way that you can contribute, that is very helpful to the scientific and medical community and to the community, to the people living with MS.

And I recommend when people have interest in research and they ask me, I refer them to a website called clinicaltrials.gov. That lists all the trials for any condition, and you can type search by conditions. You can type multiple sclerosis. And then you can type another line, and then you can type if you know, like, the treatment. So, you want to look at MRI. And you can choose, are they actively enrolling? Is it completed? Is it based on state? So, you can see what's out there. And even if you just want to know what they are studying in MS, let's take a look, right? So that's another good resource whether you want to participate or not. You know that that's a way of receiving and also giving back to the community, if you wanted to do something like that.

Yahaira Rivera

Wonderful. Thank you so much, and I think it's important to also, in case someone is listening to this recording and they might not be ready to be part of a clinical trial, there are other ways to participate and to be engaged.

Sometimes, like for example, at MSAA, we do surveys all the time, and we collect information from our community, information that help us identify challenges, information that help us identify topics that they would like to learn about, and that help us to develop future programs, future educational resources, so there are different ways to be engaged.

But definitely consider being part of clinical trials, representation matters, and you can always ask your provider, like Dr. Rivas, finding websites or finding resources to give you more information. And with that said, we are moving forward.

We are about to wrap up our webinar. But I would like to give once again the opportunity to Anita and Dr. Rivas to give us additional advice, a key takeaway from this conversation that you would like to give our community.

Anita Williams
We often refer to the MS journey in general, and that was one of the first things that I was told when I called and spoke to someone about having MS. And they said, “Your life is still a journey, you just have MS with you.” And so, in different situations, we always hear the word journey.

And the way that I feel about it is you are driving your car. You're driving your MS car. That means that you can go, you can stop, you can pull off to the side of the road and take a break. But what it ultimately means is that you are in control. So yes, driving, but that means you are in control. And that also means that the self-advocacy is something that you can do for yourself and something that you take with you on the road with you with your MS. Finding help with your community. is something that you can take with you. Being a teammate with your hitchhiker, with your hitchhiker on the side of the road who is your specialist. All of those things are available to you.

But remember, ultimately, it's about you. And this is a point where it's okay to be selfish. Think about yourself, what you need, how you can make your life with MS more enjoyable, more comfortable, more livable, but ultimately also have that room for other people to help you, to assist you, and to be a part of that journey. Because everyone there cares and is there to help you and help your life to be better. So, remember, you're in control, but there's also people there to help you. And you can do this. You can do this. You can.

Dr. Erica Rivas
Anita, you said it beautifully.

I don't have anything else to add to that. I mean, this is the best closing message for our people living with MS and for those supporting the people living with MS. Absolutely. Thank you, Anita. That was beautiful.

Anita Williams
But also thank you, Dr. Rivas. What I have learned from you during this conversation, the takeaways that I'm going to have, that you have gifted not just to me, but to everyone listening. Everything that you have said about your participation, your viewpoint, sharing that with us is absolutely a gift because it's something that I would say the vast majority of us have not had the opportunity to hear and to learn about and to feel from you.

That caring for your patients, it really comes through and it helps me, you know, feel comfortable, even more comfortable going to my appointments. Just because I'm a self-advocate doesn't mean I can't learn. And so, I thank you for opening yourself up and sharing with us, you, and how you're feeling. And that is immeasurable.

So, I thank you for being so open and I've gotten a gift from you, and I know that everyone listening has. Your time, your insight, thank you for bringing that to us. So, I just- that's all I have to say. Just thank you so much for bringing that perspective.

Yahaira Rivera

And on that beautiful note, we are finishing up our program. I was honored to share this platform with you, Anita and Dr. Rivas. You both brought realistic examples, real life applications and strategies and just candid conversation and humor. It was just a beautiful conversation and I'm so happy that I was able to capture these with both of you and offer this recording to our MS community. What a better way to celebrate, having this conversation with a provider and a lived experience expert. Thank you so much for your contributions, your insights, and your time.

And for everyone watching, please take a few minutes to complete the brief survey. You can do that by scanning the QR code with your phone. Your feedback is always important to us because we use it to develop future programs and to improve what we do.

And on behalf of everyone at MSAA, thank you for joining and have a wonderful day.