



Self-Advocacy in Action: Empowering the MS Community

Presented by:
Diana Andino, MD
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Yahaira Rivera:

Good evening and a warm welcome to all of you. Thank you very much for joining us. My name is Yahaira Rivera and I am the Director of Mission and Program Development for the Multiple Sclerosis Association of America. And I have the pleasure of being the moderator of this program. Today, together with Dr. Diana Andino, a multiple sclerosis neurologist, and Meghan McVeigh, a member of the multiple sclerosis community, we'll be exploring the topic of self-advocacy in action. This program is part of our educational series dedicated to the Hispanic/Latino community and is made possible thanks to the generosity and support of our sponsors Genentech and Novartis.

Hi everyone! Welcome and thank you for joining our Advocacy in Action webinar.

In case this is your first time joining us, I want to take a moment to give you some information about our organization and the services we offer. The Multiple Sclerosis Association of America is a national nonprofit organization dedicated to improving the quality of life for the MS community, and we do this through support services. Our services and programs include a toll-free telephone line that provides services in English and Spanish Monday through Friday from 8:30 a.m. to 8:00 p.m. ET, an equipment distribution program with products designed to improve safety, mobility and also help with heat sensitivity. We also offer educational programs, digital resources and publications to keep you informed. Many of our resources are available in Spanish. So for more information about these programs and services, I invite you to visit our website, as you can see on the screen. You can also call us, email us and follow us on social media.

During tonight's show, you will be able to submit your questions using the Q&A tool. We will do our best to answer questions at the end of the presentation. We ask you to please help us by completing a short survey that will appear on your screen at the end of the program and you can also access the link in the chat. So, if you can let us know what you thought of today's learning and if you have suggestions, they are very welcome. And lastly, I want to let you know that this program is being recorded and will be available in our digital library in the coming weeks. We

want to remind you that this program is for informational and educational purposes only and does not constitute formal recommendations. If you have any specific questions or concerns about your diagnosis or treatment, we recommend that you contact your doctor or healthcare provider.

Now, I'd like to welcome our guests tonight. We are very happy to have Dr. Diana Andino with us. She is a multiple sclerosis neurologist, currently serving the Austin, Texas community and is a member of our organization's Hispanic and Latino Advisory Board. I also want to welcome Meghan McVeigh, who is a healthcare professional and member of the multiple sclerosis community. Welcome, Meghan. Thank you for being here. Welcome, Dr. Andino. Thank you very much for being here with us. Welcome. And now. I'll pass the presentation to you.

Dr. Diana Andino:

Thanks for the invitation tonight. Welcome to all the people who are watching us online. The presentation we are going to have now is about advocacy so that you can communicate better with your doctors and the care team that you have. The learning objective of this presentation will have several parts. For example, we will understand the importance of self-advocacy and the management of multiple sclerosis and how it helps us raise awareness about systemic cultural barriers and provide strategies to overcome them and thus make informed decisions about their care. We also want to give you a vote of confidence in yourself and build the confidence you already have so you can discuss treatment options for your symptoms and concerns with your healthcare providers. We want to foster the empowerment of connection in the community to have support for each other and have motivation to continue pushing ourselves and participate in the active care of patients with multiple sclerosis.

When we talk about "*self-advocacy*," what it refers to is advocating for yourself, which is the ability to practically recognize, understand and communicate specifically and effectively the needs that you have or the needs of other people, such as friends, family, social workers and/or health professionals. In the context we are talking about today about multiple sclerosis, this means that people who are living with this disease can learn more about the disease and understand appropriate treatments and seek and demand appropriate treatments from providers. There are many resources available for people living with multiple sclerosis, so we have to learn how to obtain those resources to improve quality of life. Also, it is important that a priority is created to care for this. As a doctor, if you don't know what a patient is going through we can't really help them. So, if you don't communicate with us about your needs, we won't know the challenges you are facing. So it is very important that you communicate with us.

Self-advocacy is important, as we said, so that you can express what you need. We have to make informed decisions and you also have rights as patients, so you especially, as someone who has multiple sclerosis, has rights that you have to assert. A way to ensure access to appropriate healthcare with accommodations, for example, for the work help you need and support networks around your city or community, and understand how to access those resources as well. The importance of this is to build confidence and most importantly of all it is to foster the resilience that you have in yourself from a condition that is so chronic and that, as you know, multiple sclerosis can cause many things. So we can never predict unless we know what they may need at that time.

Several concepts that have been formed through different studies in the past, and this is a very interesting concept, **The Three Cs of Advocacy**. For example, when we are talking about self-advocacy we can understand it in three different branches, as you see in the figure in the center. For example, the first concept is **connect**, which refers to having relationships with

people who are in key groups around your cause and who can help you and offer you support. By connecting with people who understand what you are going through, you gain allies and ensure that your needs and advocacy and whatever you need is heard by the right person who needs to hear it. It is important that you can **communicate**, and that is the next C of this concept. Communicating means being able to effectively express your needs, ideas, concerns, and clear communication ensures that your message is understood and allows you to involve others in dialogue for your cause. By having these two concepts of connecting and communicating, then we can begin to **collaborate** with each other. Collaborating with your doctor, collaborating with your social worker, with your health insurance, with your friends, with your job, together you create a team that can work together to strengthen your efforts. Collaboration increases the impact of bringing together perspectives that are diverse, having more resources available, and overall truly supports being able to make changes that are favorable for your future.

Part of the strategy for how you can be a better advocate for your own care. We know there are many things we could say right now, but we want to focus on several branches from different parts, for example, it is important that you know yourself. Each person has strengths and weaknesses, and the first time you start practicing self-advocacy, you may feel quite uncomfortable, and it is not necessary to be perfect with how you say things or how you do things at first, but it is essential to be able to take control of your health, you can strengthen those moments and see where you excel and the areas you might need support. It is practically creating an awareness or self-awareness that can guide your conversations and decisions in the future by understanding what parts of your life are strengths and what parts of your life are your weaknesses. By the time you have a better understanding of that, you can create a better version of yourself. You may have a few more options to be able to communicate about treatments and learn how to have a relationship, and how those different symptoms relate to MS, and so know what's going on with your body and how we can help you.

In many countries, including the United States, there are rights that every multiple sclerosis patient has. So it is important that you know your rights as well. I recommend that you familiarize yourself with the laws of the United States, for example, the Americans with Disabilities Act, which is called by its acronym in English -the ADA. These training laws virtually prohibit discrimination against people who have disabilities in all aspects of life, including public places, workplaces, schools, transportation, and private places open to the public as well. So one has the right and can use these laws to remind people that they were doing something not very proper in their workplace, for example. In school settings, many of the patients initially diagnosed with multiple sclerosis need to have a little extra time to complete assignments or accomplish projects. So that is also something that we can ask for as a right that they can have more time to complete their studies or have specific places that can do their work as well.

Another thing, what is called in English the "handicap plate," which is practically having a right to have a disability plate that can help you when driving or when you have to park in different places so that it can be close to you at all times without having to walk a lot, or go to events that you can enjoy with your family and not have that worry that you can't be in a place that you can't get to or that you won't be able to walk. So all those things are rights.

The other concept was knowledge that facilitates self-advocacy. For example, the more you understand multiple sclerosis yourself and educate yourself about its symptoms and know more things about yourself, that will help you make better decisions because you will be more informed about the symptoms. And at the same time you can ask the right things at doctor visits and have concrete symptoms or concrete ideas that you can discuss with your doctor. When

you are preparing for your visit, for example, you need to be your own best advocate for your own care. As we say, if you don't tell us anything, we won't be able to do anything either, because we don't know what's happening. To prepare, it is best to take the time necessary so that you can reflect on the priorities you want to discuss at that medical appointment or with your pharmacist, with your health insurance, with anyone who is being seen at that moment. But, take written notes from a list or on the phone, make a list of messages so that you keep your key points of what you want your doctor to answer at that moment. Tell them the things that are going on that you are having difficulty with, but we are also happy to hear when you are going to do things that you couldn't do before, for example, that now you can take care of your child better and you no longer have to ask the friend to do it, picking them up from school, for example. These are things that are very important to your daily life and we want to hear that too.

Don't be afraid to talk to your doctor. Sometimes, because of culture or because you are not used to saying what you think, you stay a little quiet, but in a respectful way, obviously, with your doctor, you can make sure to express everything; what you need and to tell us what you feel. What you need is very important too. With multiple sclerosis, you will have many days that are up and down and it is important to have a very good relationship with people you trust around you. We can have friends or family who accompany you to the appointment or who help you build other local support groups or also online, as happened with the entire pandemic that became super popular. Have a support line group as well and building relationships that are solid, that can help you in the future. Unfortunately, multiple sclerosis does not have a cure yet, so we know that this is a chronic disease and it is important to have people who can help us in the future as well.

When you have a doctor who is going to be your multiple sclerosis caregiver, it is important to communicate it in a way that you as a patient are going to be the center of everything that happens around you, and having that attention focused as a patient will be to encourage more active collaboration and be able to make shared decisions. In English there is a concept called "*Shared Decision Making*," which practically means that the patient, family, doctors and anyone in charge will be provided with personalized and comprehensive care for the entire patient themselves. The idea of this is that they will be with the values and mission that is really what the patient needs, that it is coordinated care and that they can access everything they need, that we can not only take care of physical things, but also emotional ones. and everything that is important and a priority for you. When we find, for example, Latino families or those who are from other family units, it is important to see the family also respecting the options, obviously of the patient, but it becomes an integral part of the family caregiver. When we find that type of transparent communication and we can communicate directly with the doctor or anyone who is caring for you at that moment, all the information becomes easier to understand and you will feel more welcome and more comfortable being able to tell us everything you need.

In the cultural context, when we talk about self-advocacy, again, as we said, it is an essential part of having the management of multiple sclerosis and it becomes much more important when a Latino or another person who has a nuclear family because they are coming. The family, cousin or other family is going to find out who came out with MS unexpectedly and those cultural or systemic factors can affect the person's ability to advocate for themselves. Sometimes I don't know, as it is unexpected news, it is crucial for the entire family to be in charge and learn together the challenges and strategies to improve the care itself, but also to be their own advocate. There are people who do not speak the language, who may have language problems or do not have the level of education to understand all the ramifications that it can have with multiple sclerosis. So it is important to take the time to find support groups or community networks or organizations like MSAA that can understand in the same language or

in a simpler way explain what multiple sclerosis itself is and meet other patients who have the same thing. It is important to have the right education tools and support so you can navigate this path with more confidence. The most important thing, with autonomy, because you are the one who has this disease. So that's more important than having control of your health.

In the cultural context there are certain different concepts that we are going to touch on here in general, and then a couple of questions as well just after that. For example, in how we continue to talk about the family approach, the family, as it plays a central role in the lives of many people, especially Latinos or from other cultures. That can have implications, either as good, supportive or negative that can have some negative impact on care as well. It is important that you learn to express your own health care preferences if you need someone to be with you at your visit, or if you prefer to do that visit alone, you have the right to decide that while respecting each other's family values. In terms of respect, there are many cultures, not only Latin, but also others that have an authoritative presence or someone who is an authority figure, including doctors who are a little afraid to speak there in front of the appointment. At that time, you can also respectfully call out, question or challenge medical advice if that is not something you sort of agree to. It means that you need to have the balance of respecting medical professionals, but with the confidence that you can ask questions, express your concerns, and even seek second opinions. Your doctor does not need to be the only doctor you see your entire life. You may have other options during your care as well.

There is a concept called "*fatalism*." There are people who find themselves believing that health outcomes are predestined, that no matter what they do they already know that nothing is going to turn out well for them and that everything happened to them because it was something that was already in their destiny. But it is important to educate ourselves about what we can do to counteract this belief and know the importance of proactive things such as treatments or lifestyle adjustments that can help counteract these attitudes in many people. At the same time, we live in a country full of immigrants, and the language barrier can create many limitations for some people, since English is not their first language. The difficulties remain in understanding medical terms because that is another language entirely, treatment options, the process of advocating for themselves and everything becomes more complicated. It is important that you make sure you have access to interpreters, bilingual doctors or bilingual health professionals who can help you express your needs better and that you have the confidence to communicate with your doctors.

Socioeconomic factors are also something that greatly affects the cultural context. We know that it is something that everyone has a part of conscience that access to medical care is very inaccessible, but it is important to have medical care that is of quality and that you can go often to be sure that you are receiving the necessary care. Sometimes you don't have health insurance, the insurance is not enough, or you don't have enough insurance to pay the co-pays. So it is important that you contact your doctor if that becomes a difficulty so that we can find resources through organizations that are *non-profit* or other foundations that help us cover those expenses, too.

Health education is the most important thing so that you can strengthen yourself and have better confidence and self-advocacy in general for people living with that condition. The more you know about your disease and what the symptoms are, or progression, or treatment and what to expect, why I need to have the tests or the MRIs or the labs. All of that is necessary. You have to understand why that is being done and that way you will be empowered and be able to make better decisions with your doctor. There are places that can offer resources in English or Spanish or whatever language you prefer and can incorporate it during the time of

teaching your family or friends about your illness as well. Organizations like this, the MSA, which is a patient advocacy group or local support networks for patients living with this condition, is a very good resource that can have connections with other people who also live with multiple sclerosis, because the Health is quite complicated here in the United States. As we say, getting back to knowing your rights and finding others who are your allies in your health is important too.

These are different organizations that we wanted to mention during this presentation. But there are several chapters or local units of these organizations that can connect. The important thing is that you have access to this. So if you want to take a photo of this page and from there you can go to each organization and see what they can offer you and how you can connect with other members who are living with MS as well.

A moment of, not only for you, like self-advocacy, but it is the change of policy at the government or national level or at the State level, you could say. The power of self-advocacy to change policy is very important because it can empower us as people to question or challenge current government leaders in order to influence and change legislation and policies. And at that moment we can begin to change the change we are giving to patients living with multiple sclerosis. It focuses on driving changes that improve access to health care or access to medications through their health insurance or have technology that is more assisted or that they need and more support in the resources they need to live day to day. Government officials can promote these laws and you as a patient can go talk to these representatives and tell them your story of the difficulties you are having. At that moment they start to get another idea that the laws they are writing or having in front of them can really cause a negative or positive change to the patients. And the fact that you are telling your story is very, very important in being able to change coverage or linkage to research or access to treatment, or the way MS patients are cared for in your area as well.

So, now I wanted to invite a patient, Meghan, who is also joining us now so that she can explain a little to us about her care with multiple sclerosis. Thank you Meghan for being here.

Meghan McVeigh:

Thank you. I'm really excited to be here and represent what it means to be a person who has multiple sclerosis.

Yahaira Rivera:

Meghan is a multiple sclerosis patient and she is here with us today to share part of her experience. So now we are going to move on to some questions that we are going to have a dialogue between the patient and the doctor and we are going to translate them. Okay, Meghan, our first question is: How can patients with multiple sclerosis educate themselves about their diagnosis and treatment options to become active participants in their healthcare?

Meghan McVeigh:

So, one way that patients can educate themselves about their diagnosis and treatment options when it comes to having MS is utilizing the internet. There are plentiful resources online, the National Multiple Sclerosis Society, a lot of the sponsors for the presentation today. Their websites include pages dedicated just to resources that expand for being a patient, the financial aspects related to getting treatment, there's resources to help find a specialist in your area who is accepting patients and can see you and be able to build those relationships. There's also a lot of online support communities that you can interact with others from all over the world who have

multiple sclerosis, as well as local chapters within your immediate area that you can meet with people face to face, and it provides a really... It makes you feel less alone. I guess I could say. Knowing that even though this disease is very much invisible, there are people around us that experience the same symptoms and struggle in the same ways and you're not alone.

Yahaira Rivera:

Thank you, Meghan. Okay, so Meghan is giving us advice to become familiar with patient advocacy organizations, as well as us, the Multiple Sclerosis Association of America, and other organizations. Also, look for information on the websites of these organizations, because the information offered there is scientific, based on facts and can help you understand multiple sclerosis, find resources, find information to help you and also others. their families to understand the disease. He also recommended that you look locally in your community for doctors specializing in multiple sclerosis so that you can begin to network, to begin your treatment. And Meghan also recommends that since this disease is an illness that has many invisible symptoms, that you also seek support, support in local groups, in online groups, on the internet and so you can relate, have a bond with other people who are living the same disease and feel that you have support not only in your family, but also with other people, not necessarily friends or families, but people who, like you, have some of these symptoms, have the same condition and can learn and support each other. each other.

Ok, our next question: What role does communication between patients and healthcare providers play in successful self-advocacy and how can patients ensure their concerns are heard? *This question is very important and is asking Meghan - what roles does communication between patients and doctors or healthcare providers play in the success of self-advocacy? How can patients ensure that their concerns are heard?*

Meghan McVeigh:

Thank you. So, the most important thing about communication is, for me, it is the most vital role that you can play when you establish a relationship with your healthcare provider and the doctor who is overseeing your care when it comes to multiple sclerosis. Preparing yourself before coming to the appointment and understanding that their level of understanding the disease may outweigh your own. But they are there to support you, guide you through, and ultimately take care of you as you have MS. Writing notes down and sharing your personal symptoms and experiences you may have, whether you think that they are related to your MS or not, and going in with an open line of communication is extremely important when it comes to your healthcare provider and your relationship with them and advocating for yourself. It's better to over-share things that you're experiencing, because, even if it's not related to your multiple sclerosis, it can provide you a sense of peace knowing that not everything is ultimately because of your MS, you just happen to have MS. So, you're going to experience things that, and learn things, I guess, through your journey that are because of the disease, but not everything you experience is going to fall back on the disease.

Yahaira Rivera:

Okay, so Meghan is giving us some good advice. First, maintain open and honest communication with your doctor or your medical team and write down your questions, write down your concerns, come prepared to appointments to make the most of your time and when you are with your doctor or your health care provider that Share everything, everything you have felt, all the symptoms, all your concerns and questions, which sometimes is better to share more than not share. And so the doctor can determine if what you, the symptoms you've had, what you're experiencing, is related to multiple sclerosis disease or perhaps related to some other

condition. So she recommends that you maintain that communication, that trust with your healthcare providers. Sometimes they know much more than us, than you as a patient, that's why they studied, that's why they do research and that's why they read and educate themselves. But you can trust that the doctor wants the best for you and that if you don't agree with something or have questions and concerns, always feel free to share it. And since sometimes a lot of time passes between one appointment and another, he recommends that you take note of your questions, your concerns or any changes. And so, when you go to the appointment, you maintain that communication with your doctor. Okay, now we're going to move on to the next question... oh yeah, go ahead.

Dr. Diana Andino:

I think things that... I think you don't really well, Meghan, because I get to be your physician, which is an honor. If you actually reach out in between your appointments, and that saves some time to not delay your care or... answer questions that you may have in between that, so I think that's something that patients should do as well. One of the things I have the honor of caring for Meghan as a patient is that she also does not wait for appointments to have a question, but if something is happening immediately or she has a question or new symptom, she lets us know as soon as she feels something for us to decide if it is something important that needs urgent care or if we can wait for the appointment. And it becomes like in terms of trust between the doctor and the patient, being able to have that relationship.

Meghan McVeigh:

So, really quick, I just want to thank you for saying that Dr. Andino and I am honored to be your patient. It's been an amazing experience, and I can't... I don't want to cry, but I can't express how much comfort you've provided me through our journey. And knowing one of the best questions that I did ask you and that I encourage anyone with MS to ask their healthcare professional and their doctor is when should I contact you between visits? It's not... since MS is an extremely unpredictable disease, patients shouldn't feel like they only have the small window of time that they're in the appointment that they can speak to the doctor and knowing that there are online patient portals and resource numbers that you can call and making sure that your provider and yourself have established a good protocol or game plan if your symptoms are new or they extend for a certain period of time that you should reach out and you should feel encouraged and know that you're never going to interrupt your doctor. They want to speak with you. They think about you when they're not with them. And I know I'm not a doctor, but I know for sure that doctors carry all their patients in their heart, and they will always think of you. So don't think that you are bothering them. If you feel like something is wrong, find a way to speak up and make sure you have the resources of numbers you can call to reach your doctor in the event that you need to. And that's also comforting as well, because you don't know how you feel every day when you wake up, every day you could feel a little different or you could feel the same, so knowing you can reach out to them and the open communication is available is really comforting.

Yahaira Rivera:

Okay. That's great advice, thank you so much. And we are so happy that you both share your experience with us. Thank you. Thank you very much for sharing your experience as a patient doctor. I'm going to try to summarize all the advice that Meghan just gave us. She recommends to us... First, Dr. Andino and Meghan have a very beautiful relationship and a lot of respect and communication, they are doctor-patients. So Meghan recommends that you talk to your doctor or health care provider, ask, between visits, how you can communicate with them. Because sometimes you have to wait, for example, a period of six months or perhaps even more, and

since multiple sclerosis is an unpredictable disease, there may be changes that were not expected, you should ask your doctor in between those appointments in that time if something happens to you, if you have questions or need help, how you should contact your doctor. There are clinics and doctors who use online portals. It is as if it were a Messenger, like a chat where you can write messages and the nurses or your own doctor will answer you. There are other clinics that give you a website or a telephone number where you should contact. So that will help you and your doctor stay in communication during the waiting period for the next appointment or follow-up. So, some good advice from Dr. Andino and Meghan today.

We continue with the next question. Next question. In what ways can healthcare providers support their patients with multiple sclerosis in overcoming potential barriers like language, cultural differences, or financial challenges to access care and resources? *This is a very important question and perhaps Dr. Andino can't help us a little with this one. How can healthcare providers support patients with multiple sclerosis to overcome potential barriers, such as language, cultural differences, or financial challenges so they can get the healthcare and resources they need?*

Dr. Diana Andino:

I'll share first, Meghan, and then you can jump in, after this one.

Meghan Mcveigh:

Sure.

Dr. Diana Andino:

As a provider we have many resources that we have access to in the clinic in some locations, but in many clinics the resources are more limited. But when they are language, all clinics must have an interpreter, either in person or by video, who is available to all patients, so that communication is in their language. That is by right and by law in the United States. So it is usually easier when the patient and the doctor speak the same language to be able to communicate, but when the same language is not possible, at least always have an interpreter on hand. In terms of cultural differences, I conducted many of my visits, for example, bilingual, with the patient who feels more comfortable speaking English and with the family and the person there with the one who speaks Spanish. So both languages are used and I allow them to bring their families to the appointments as well, which is very important. There are times that I make different appointments just to have another conversation with family members. Having that time available to them and understanding that that is important as a doctor is very important. In financial terms, you can access resources from doctors, whether it is financing to be able to make payments for each visit or having some other non-profit organizations like you also help us access some medical equipment for patients, it is very important to have that relationship. , and communicate with patients what other resources they need and how we can obtain them.

So, I was saying that it was mainly obtaining a same-language provider or that you have a right to have an interpreter in the clinic for all the calls and all the visits. When family members or other people who want to hear about your case or be present during the appointment or create another appointment time to share that with the family members is important, and reaching out to non-profit organizations and other places that can provide resources and finances for the care.

Meghan McVeigh:

Those are all great answers. I agree. I also want to add that as someone who works in healthcare, the doctors work with a close-knit group of financial counselors, medical assistants, people within their office that help with any of the financial challenges that can go over what your specific insurance benefits are, any, again, like non-profit resources. There's a lot of copay assistance programs to help offset the costs. So, the doctors have a network of a lot of resources. They can further extend assistance, however needed.

Yahaira Rivera:

Thank you, Meghan. So, Meghan has added to all the advice that Dr. Andino gave and all the suggestions to also be familiar with when you go to your doctor in the office or clinic where you are receiving medical care, doctors usually have access to other people in the office or clinic that can help them with information to navigate their health insurance coverage, organizations that help them with the cost of medication or with the cost of doctor visits, non-profit government organizations. So I think the point here is to ask, not be afraid and ask, be transparent, be honest, offer, ask for help and let your doctors know what you need so that they in the office or clinic can look for you. the necessary resources.

Dr. Diana Andino:

And one thing about not being afraid, Yahaira, is also the immigrant part of our culture. In other words, if you are looking for political asylum or anything, you can also seek medical help at the same time you are not independent, or if you are undocumented for some reason there are resources for you as well. So, the better - you tell us - we can help you. Part of the... as an immigrant in Texas, there's a lot of immigrants here, a lot of them are asylum seekers or undocumented, so there are still resources available for them, so they shouldn't be afraid to speak up to their doctor.

Yahaira Rivera:

Thank you Dr. Andino, very good advice. Thank you very much for that. So we're going to pass... we can move on to our next question. The next question. How can patients with MS navigate complex healthcare systems, including understanding insurance options, seeking second opinions, and finding support networks?

Meghan McVeigh:

So one way for being a patient and navigating my MS diagnosis through all of the nuances of being a patient and all the resources and treatments available is I personally have, and I would recommend someone document everything and create a healthcare binder dedicated to their care, that way you have one available place for previous MRI images, your symptoms, if you track them to kind of understand your disease more and how it affects you, that way you are fully prepared on that front, and also the knowing your insurance options, any second opinions if you do see another specialist for MS or you travel somewhere either out of the country or to another part of the country. It helps to keep it all in one place, that way all of the information is available and nothing gets forgotten.

Yahaira Rivera:

Good advice that Meghan just gave us. She says that as a patient, something that she does and that she also recommends to you is to create a system, like a folder, a folder, an organizational system where you can continue accumulating your results, your analyses, where you can write down, As we say in English, a "journal," like writing down a notebook or notebook where you can keep information about your symptoms, their changes, the documentation they send you

from your health insurance or if you go to different doctors until the diagnosis is confirmed or if change doctors. You continue to accumulate all that documentation and so if you travel to another doctor, travel out of the country or travel out of state, or need to gather information, you have everything already in one place and it becomes easier for you to manage all that. Any other opinions, Dr. Andino, or any other advice?

Dr. Diana Andino:

That is very important, because if we do not know what happened to them a couple of years ago, we are going to repeat many things again and double the money will be spent for the patient. So I very much agree with that. The other thing is the healthcare system in the United States has different forms of academic, community private, public, all of this. So it is important to know which system is best for you, in that it feels more like it is easier to get to a clinic that is close to you even though it is the community. No matter that, it is preferable to have the resource closer than to travel an hour, two hours to see the specialist, which is the hour you can see twice a year. So it's important to see what works for you personally and not who is the best doctor in town, relatively. The binder idea is amazing and I think you do a wonderful job with that, Meghan. Because, if not, we're going to be repeating things that you already did several years ago and you're just going to spend twice as much. There's different systems of healthcare in the US, like, there's academic, community, local, all those different things. So, I wouldn't recommend to look for the best doctor in town, I think you should look for the most... "your" doctor in town should be the preference. Whatever setting that works for you, your local clinic, if that's the case, or if you prefer an academic center, I think that there's a place for everyone. So just knowing that. There is a place for each of you. So, as long as they know where you feel most comfortable as patients, the most important thing is.

Yahaira Rivera:

Thank you, Dr. Andino. Okay. Well. Questions and answers from the audience. Our audience has been attending the presentation and we have not received any questions, but we did receive questions during registration for the program. So I'm going to use those questions before we conclude our seminar. What are the signs that I need to start advocating for myself? So, this question is a patient asking if there is a sign where I can realize, like, I better start self-advocating for myself, if that makes sense? So, do you have any advice or when did you realize it was the moment to self-advocate for you?

Meghan McVeigh:

So, my experience with MS and when it first started for me was I did not self-advocate. I had a very mild symptom that I told myself was not anything bad. I thought it was a pinched nerve and I went several days without speaking up. And by the time I contacted a doctor and verbalized my symptoms, I ended up in the hospital. So, for my personal experience, I learned the hard way, and I don't want anyone else to learn that way. It's not pleasant. But, I will say that even though self-advocacy is hard, don't talk yourself out of it and understand that any little thing could mean that you're potentially having a flair, and advocating and speaking up about how you're feeling could avoid you having to be in the hospital. And I don't think anyone enjoys being in the hospital.

Yahaira Rivera:

Thank you, Meghan. So Meghan is telling us that when she began her journey with multiple sclerosis, she started with pain in her back and she thought it was a nuisance and didn't say anything. And he held on and held on and held on until he ended up going to the hospital. So she recommends that whatever you feel, don't be afraid to talk, talk about it with your family, talk

about it with your doctor, because with this condition it is very important to notice the changes, notice the symptoms, but above all, advocate for yourself and take care of yourself. . That's very important.

Okay, our next question is: As Hispanics, oftentimes we are scared or we don't ask doctors questions, thinking that is a lack of respect. How can they move forward from this?

Dr. Diana Andino:

The patients and appointments that scare me the most as a doctor are the ones that last like ten minutes and it's over because I know they're not really telling me what's going on at home or with their symptoms. So it is important as a doctor to present that I do not know everything. So you have to tell me what's going on. And it's a part of education for the doctors themselves more than for the patient, so that they can have the patient feel comfortable telling the doctor things. But it is important that the patient has their symptom diary and really tells us what everything is happening, that they do not have the fear of that, but it is a quite strong cultural change. But doctors are nothing more than people just like you, so don't be afraid to not communicate with them. Some of the worst appointments that I have last ten minutes because they are not telling me anything that they should be telling me, so those are the ones that make me more afraid. But, if the doctor doesn't feel comfortable with the patient, they won't raise those concerns. So, it's important that the doctors, we educate ourselves too, to know how to be perceived more comfortable and the patient has more confidence to be able to share what they have; to tell us

Meghan McVeigh:

I agree and I also think building a trustworthy relationship with your doctor is very important. Dr. Andino and I have a really good understanding of one another so far in our journey together and she has provided me a comfortable, safe place that I can speak up, and she knows that my communicating of whatever my needs are, that it's coming from a place of uncertainty and needing assurance and confidence that I'm getting the care that she devotes her life to provide. So, I think making sure you have that relationship with the right doctor for you, ultimately, will create that safe space to speak up without fear of being disrespectful.

Yahaira Rivera:

Thank you, Meghan. Meghan is giving us advice. The experience she has had with Dr. Andino has been very positive, very beautiful, she has a respectful relationship and she is confident that the doctor is offering her the treatment and care that is best for her. And Meghan is recommending that you should do that, and if you don't have that kind of care, you should then make calls to your health insurance, find a doctor who will listen to you where you can express yourself, where you feel respected and are not afraid. to advocate for yourself, because that's what's important. Before we say goodbye, do Dr. Andino or Meghan have any last advice? Any last words you want to share? Before we wrap up our amazing webinar tonight, do you have any last word of advice for the audience?

Dr. Diana Andino:

Tell us what we need to know. Don't be afraid to talk to us as a patient with a doctor. If you don't tell us, we won't know, if I think it's the end of the comment. Tell us what we should hear from you. If you don't tell us what you feel, then we can't help.

Meghan McVeigh:

And that's great and it's so important. And I would love to leave off to other people who are watching this who also have MS and just say that when I was first diagnosed, the fear and the uncertainty, and that, when we spoke about the fatalism thoughts, while they run through your head, there is a really good quote that people say through the National MS Society that stays with me and it's very short, it's: "I have MS, MS doesn't have me." So, knowing that through self-advocacy you are still the person you've always been, that you still have an opportunity to live a very full, beautiful life. You may have to make some adjustments to your life, but it's not the end of your life. And I've been battling MS for about two years since the symptoms came on. And two years ago, I would have never thought that I could be where I am today. Through the help of Dr. Andino and my medications and all of my documentation and educating myself and self-advocacy, I can work a full-time job, I have young children that are even as little as two years old. I run on a treadmill. I run, first of all. That was something that I couldn't always do. I lost the ability to walk for a while. So, you learn so much more gratitude for the little things in life, and your doctors and your care team, they all want to celebrate all of those wins with you, not just because of your MS, but because of who you are and they are there to help you and support you and guide you to make sure that your life stays as beautiful as it can be and you keep going, always keep going. You have MS, MS does not have you.

Yahaira Rivera:

Thank you, Meghan, that was beautiful. Meghan is telling us that when she was diagnosed her mind was filled with worry and fear, and that fatalism that we talked about a little while ago that Dr. Andino was describing. But thanks to her efforts to educate herself, learn about multiple sclerosis, understand her illness, and of course the blessing that she has an excellent doctor who has given her treatment, who helps her, Meghan previously had problems walking and now, after Two years after her diagnosis, she has taken care of herself, she is undergoing treatment and she has learned that although she has the condition of multiple sclerosis, that chronic disease, that does not define who she is as a person. She is a woman. She is a mom. She is taking care of herself. He can even run, exercise, and find gratitude and the beauty of life every day despite having multiple sclerosis.

And with that thought we say goodbye tonight. We thank Dr. Andino and Meghan again. Tonight's topic was very important because we know, what we have learned, that a patient who knows about his condition, a patient who knows how to defend himself, who stays informed and who takes an active role in his care plan, is a patient who You will have a better quality of life and better results in your treatment plan. And as Dr. Andino told you, don't be afraid to talk and share what you have to share with your doctor.

So thank you very much, Dr. Andino and Meghan. Thank you so much Meghan, and we were honored to hear your experience as a patient, and Dr. Andino, her experience and perspective and great advice as a provider. So, thank you both. Have a nice night and I hope you enjoyed learning a lot. Take care of yourselves and until next time.