



# Shared Decision Making and Adherence to Treatment in MS

Presented by:  
Gabriel Pardo, MD, FAAN  
Julian Gamboa

## **Yahaira Rivera:**

Hello. Good evening. On behalf of the Multiple Sclerosis Association of America, I extend a warm welcome to all of you. Thank you for connecting and for participating in our seminar: Shared Decision Making and Adherence to Treatment in Multiple Sclerosis, which will be presented by Dr. Gabriel Pardo, a multiple sclerosis specialist, and Julián Gamboa, a member of the patient community living with multiple sclerosis.

My name is Yahaira Rivera Bobadilla. I am the Director of Mission and Program Development for the Multiple Sclerosis Association of America and I will be your host this evening. This seminar is part of our series ***Together Finding Resilience: Living with Multiple Sclerosis***. This initiative of educational resources and programs is specially designed and dedicated to our Hispanic and Latino community living with multiple sclerosis. This program is brought to you by the Multiple Sclerosis Association of America, in collaboration with Impact Education, and is made possible through the generosity and support of our sponsors, Biogen, Bristol Myers Squibb, Genentech, and Sanofi Genzyme.

For my English speakers, welcome and thank you for joining MSAA's live webinar Shared Decision Making and Adherence to Treatment in MS. As previously mentioned, this webinar will be presented in Spanish, but please know that the presentation slides are being provided in English and Spanish, so you are more than welcome to stay along, follow us, and enjoy the learning. *Next slide.*

Before we begin, I would like to take this opportunity to give you some information about who we are and our services. The Multiple Sclerosis Association of America, better known as MSAA, is a national non-profit organization dedicated to improving lives today for the multiple sclerosis community through vital support services. Our services include a nationwide helpline that provides services in English and Spanish, Monday through Friday from 8:30 am to 8:00 pm Eastern Time. We also have cooling vest and gear distribution programs with products designed to improve safety and mobility and to help with heat sensitivity. We also have a MRI access fund. Both of these programs are available to people with multiple sclerosis who qualify for assistance. We also have educational programs, like tonight's presentation, tools, publications, and digital resources to keep you informed about multiple sclerosis. And finally, we also have Community Connection to help you stay in touch with other members of the community. All of our programs are available to people living with multiple sclerosis across the country. For more information, you can call us, visit us on our website, or follow us on social networks. *Next slide.*

We want to remind you that this program is for informational and educational purposes only and does not constitute recommendations provided above. If you have a specific concern or question about your diagnosis or treatment, you should contact your doctor or health care provider.

I also want to let you know that during tonight's program you will have the opportunity to ask us questions and to participate with your comments and suggestions. You can also use the chat or the Q&A icon. At the end of the seminar we will have a question and answer talk and we will do our best to answer your questions.

I also want to remind you that during tonight's program we will be recording the entire talk and you will be able to access it in our digital library during the next few weeks. And at the end of the seminar you will have access to a short survey. We ask that you please fill out the survey to give us your comments or suggestions and tell us your thoughts to help us develop future programs and themes. *Next slide.*

Tonight, together with Dr. Pardo and Julián, we will explore how shared decision-making facilitates adherence to treatment, how people living with multiple sclerosis can engage effectively with their care providers, and how adherence to a personalized care plan grows, and it is strengthened when the doctor-patient relationship is cultivated. *Next slide.*

And now, without further ado, I want to introduce our guest speakers. Today we have with us Dr. Pardo. Dr. Pardo specializes in the treatment and research of multiple sclerosis and other related disorders. He is the director of the Oklahoma Medical Research Foundation's Multiple Sclerosis Center of Excellence and an associate member of the Oklahoma Medical Research Foundation's Clinical Immunology Research Program. Dr. Pardo completed his training in the fields of ophthalmology, neurology, and neuro-ophthalmology and has been dedicated to the area of neuroimmunology for more than two decades. He is certified by the American Board of Psychiatry and Neurology and sits on national professional committees dedicated to the advocacy of multiple sclerosis patients.

We also have with us Julián Gamboa. Julian received his bachelor's degree in marketing from the University of California at Berkeley and led the Telemundo Los Angeles company's first organic social strategy in live streaming and celebrity advertising. His experience led him to teach one of the first courses on social media at the University of California at Berkeley. At the end of 2021, Julián was diagnosed with multiple sclerosis. After connecting with Ms Gina Ross Murdoch, our association's president and CEO, he volunteered with the association and accepted a position on the advisory board. Julián helps us advocate for Hispanics and Latinos living with multiple sclerosis, especially younger generations and patients. Thank you for being here with us, Dr. Pardo and Julián. Welcome.

### **Dr Gabriel Pardo:**

Thank you very much, Yahaira. Good evening everyone. Good evening, Julian. So we're going to start our session on shared decision-making in multiple sclerosis, and what the implication is for treatment. And I think that the first thing we should do is briefly define multiple sclerosis, because it's going to give us some important elements that we're going to incorporate into the conversation tonight, so that you understand why it's so important that you be your own advocate for your health because multiple sclerosis is a very specific disease, with characteristics that are different from many other diseases.

So, briefly, what we know about multiple sclerosis, how it works, that leads to those disabilities in some cases, is the fact that we're dealing with an autoimmune disease. When we say autoimmune, we refer to a process in which the immune system in our body has a very specific function, which is to defend us against those agents that are going to cause us harm, usually pathogens such as bacteria and viruses. But in certain circumstances it gets confused. It doesn't quite understand what's going on and recognizes a part of your own body as something foreign that has to be attacked and destroyed. And that's the autoimmune part. In other words, the immune system attacks its own body and, depending on the organ that is being affected by that attack, we have different autoimmune diseases. In the specific case of multiple sclerosis, the immune system has gotten confused and believes that the myelin covering around nerve cells in the central nervous system, which is the brain and spinal cord, is something that doesn't belong in our body, which has to be attacked.

And there is a very important feature in the immune system called immune memory, which in most cases provides us with a great benefit. It means that the immune system will remember something once it recognizes it as an enemy, it will remember it for the rest of your life. And every time it exposes itself, you're exposed to that enemy, it's going to attack it. So we have a process that is going to happen for the rest of your life and to which you are predisposed to have new problems as life goes on.

When the immune system attacks the myelin, it will cause damage and compromise the capacity or ability of the central nervous system to work properly, and depending on the area that is affected in the brain or spinal cord, multiple sclerosis patients will have different manifestations. And because it is completely unpredictable which part of the brain or which part of the spinal cord will be affected, and each part has a different function, the manifestations of multiple sclerosis are extremely variable. No patient will have the same characteristics as the next patient. In fact, that confuses the initial diagnosis in many cases, because doctors aren't expecting the variety of symptoms that can occur in multiple sclerosis.

For example, a patient may present with loss of vision in only one eye due to optic neuritis. The next patient is going to present with a limp because he can't lift his foot properly, a *foot drop*. And they both have multiple sclerosis. There is not a very clear relationship between the two. Usually a disease presents in a characteristic way. If a patient has a heart attack, most people will say my chest hurts like an elephant is sitting on me. My arm hurts. We say, oh! A heart attack, right.

But in multiple sclerosis, as I mentioned, the symptoms are extremely variable. So, because we're dealing with that variability and because we're dealing with a chronic process that's incurable, we can manage it, we can control it, but we can't make it go away, we can't cure it, which is not very well recognized or understood by most people in the community, and that you have a wide variety of treatments and new treatments that are appearing and that can affect the quality of life and the characteristics of how you are dealing with your day to day. So it's a very specific disease, with a number of important variables.

All these are the reasons why it is very important that in the treatment of multiple sclerosis patients be important participants in the decision-making process. And that's what brings us to today's topic. Shared decision making. And what do we mean by that?

Shared decision-making in the healthcare system means that both the patient and the health professionals are going to share a conversation, a dynamic in which we are going to understand each other, we are going to understand who you are, we are going to understand the characteristics of your particular illness in your case, because not all of them are the same, as I mentioned before. What do you like? What are your fears? What are the things that will give you confidence? Which do not give you confidence? What is your social system? What is your family support? What is your condition of access to the healthcare system?

And with these individual characteristics of your disease, and what we doctors and healthcare professionals know about the disease itself, we are going to share all this information so that the decision we make regarding the analysis, examinations, diagnosis, the treatment and long-term management of the disease, is the result of that dialogue, of that conversation and of a shared decision, so that then those decisions are the most appropriate for your particular case, the individualization of the decision and also so that you as the patient, and you as the patient's family member, if you have been part of that decision process, understand why we make the decisions and how important it is to follow the management plan that we have specified at that time.

That is the concept of shared decision making. And it is important again that we understand it well, that we understand the disease and that we agree what you are doing as a first stage or step in this process to understand the disease better, because if you are going to be your own advocate, you obviously have to share your knowledge about your disease and how you feel, but within the context of understanding the disease, because we cannot begin to have or make demands that are not going to be conducive to producing good results in the long term.

With that, and again, putting what we are going to do in context, I want Julián to also talk to us about what he perceives as shared decision-making and its importance in this process.

**Julian Gamboa:**

Hello, thank you very much Dr. Pardo and thank you very much, Yahaira. Indeed, I am Julian. Good evening, good afternoon, wherever you are watching us. I've been figuring out this multiple sclerosis situation for a year and a half and no, it hasn't been easy because there aren't any easy answers or there are some answers that scare you. So if it took me a while to figure out, for example, and I'm sure we're going to talk more about this, but when I, for example in 2019, had vertigo for a month, I woke up one day and couldn't focus my eyes. I didn't even go to the emergency room, I just said "this dizziness has to pass". It lasted a while, but it was mostly if I turned around a little bit, I would get dizzy. So what did I do? I asked my family, because I didn't know how to find out more, and from there, it was "*heard that here*" and "*who knows what*" and the friend of an aunt had suffered from vertigo, so they recommended me to an otolaryngologist, the ear doctor, they recommended me...

**Dr Gabriel Pardo:**

Otolaryngologist is a very long word, Julián.

**Julian Gamboa:**

So I went to that doctor and he told me that they didn't do medicine, they didn't do surgery, there was nothing for vertigo other than therapy. So I did the therapy for a month, it went away and that's it, I forgot that I had vertigo, nothing more. I remember that once I had vertigo, but I never suffered from it again. Until in 2021, October, where, as Dr. Pardo said, this eye turned inward.

So, I went to several doctors, I went with families, who said it could be "*6 nerve palsey*," it may be a stroke, it may be another version of vertigo, but I never imagined it would be sclerosis. And then there are so many decisions that you have to make and so many people that you listen to about something that you don't even know about, that you're not even sure about, and you discover what you need to do is simply to start asking for help and listening to all points of view that are out there and deciding which is best for you. So it's all a "show." But anyway, yes, it's quite a journey.

**Dr Gabriel Pardo:**

That's right Julian, it's a long journey. And it is a journey that we must travel together with not only your family, your friends, but also with your healthcare team and it is very important to create that relationship. I think very important. Go to the next. *Next slide.*

Because here we can start talking then a little bit about the details of what we have been talking about. What are the essential elements in this shared decision-making? And we are going to dissect a little more in detail what is happening again. As we were commenting before, the idea is that both the patient and their relatives work together with the health providers so that we can then make the best decisions. And what are the elements to reach that adequate decision-making?

The first thing is, we want to honor and respect the right to choose. This is very important because we are going to be talking about your own advocacy, what you are going to say, raise your hand and say "but I want to, I don't want to", that is very important. And we are also going to talk a little bit about how to be able to do that in an effective way, without offending the other people who are in the decision-making process.

But we have to start from that principle and it is in fact a principle that applies to all of our interpersonal relationships. I always tell my patients when we're starting this multiple sclerosis journey, they come and visit with me and we do an initial diagnosis - we are going to create a relationship as if we were a married couple, it is from now on and it is for the rest of our lives. And we have to understand each other, we have to respect each other, and we have to listen to each other like in any other relationship. It is nothing different and each part of the relationship brings something different to it. And it helps it to grow from different points of view and we have to reach conclusions, mutual agreements that benefit us all, but obviously, in the end, that it ultimately

benefits the patient who is the center of attention. So we have to start on that principle honoring the right of choice and we're going to talk again about how we can make that process fit.

The second thing is to explore the different options. For this I would like to give you a little example of how I do the process with my patients, because it is not an easy process, right? When we start to explore the different options, we are already talking about treatments, interventions, but to get there, we have traveled a stretch, we did not get there in one go.

This is a very slow process because we have to have certainty in the diagnosis. That is first. We don't want to be barking as Americans say, "*Barking up the wrong tree.*" Right? We want... we have to have a correct diagnosis because we are going to embark on a lifelong treatment, so it is very important. And to reach an accurate diagnosis, there is a process that we have to follow.

The first thing, obviously, is the clinical manifestations. That's the fancy way of saying what happened to you. Julián told us about his experience, he had an episode of vertigo, he had an episode of sixth cranial nerve palsy. When... the lights went out. That's not good. That sounds like a García Lorca poem to me. When a patient comes and we do the anamnesis, the interrogation, we talk, tell me what happened to you, and I hear a story like Julián's, I start to think about where the problem is. Within the central nervous system, where is the problem located? We know depending on the manifestations where it should be. If he had a vertigo problem, I'm thinking of a brain stem problem or a cerebellar problem, for example.

Oh, it could also be another matter, because a peripheral problem of the inner ear that has nothing to do with multiple sclerosis. So with that initial manifestation, the differential diagnosis is very long, many options, many possibilities. But then he presents with a sixth cranial nerve, and again, I'm thinking a brain stem lesion, but in a very different place than what could have caused the vertigo. So I begin to have this concept that the patient has had a process that affects the central nervous system, which has had two important characteristics and this is essential for the diagnosis of multiple sclerosis, one that affects multiple sites, not just one, but several sites.

The second thing, that it happens repeatedly in time - the separation in space and disappearance in time. These are two fundamental criteria for understanding multiple sclerosis. And it helps us, obviously, when there are a series of additional tests, the most important being the MRI, because the MRI gives us an idea about the extent of the involvement, meaning how many lesions there may actually be when a patient presents with multiple sclerosis with the first symptom, usually in the MRI we find 10 to 15 lesions. Many of them have obviously been silent. You have not had any knowledge, perception that something is happening, but we see it in the MRI and depending on the characteristics, it gives us more confidence that this is the diagnosis. We rule out a number of other possibilities by doing blood tests and doing physical exams. And sometimes we have to do additional tests, for example a lumbar puncture, it is not necessary to do everything in all patients, but sometimes we do.

And yes, all these parameters indicate that this is actually the appropriate diagnosis. So we can start the conversation about what multiple sclerosis is. That is the first step, diagnosis, proper diagnosis. Second, that the patient and the doctor are on the same page when it comes to understanding the disease. I explained to you previously what is happening, the autoimmune process, immune memory, the risk of relapse, having more and more episodes, more and more damage, the nervous tissue in the brain and spinal cord, and the possibility of creating a permanent disability. That is the risk. And the next step, then, is what can we do? Are we going to resign ourselves to the fact that this is my future? No. There are treatments, there are interventions, and we have to look at this in a holistic way, meaning that there are treatments, but medicine is not the only thing that we are going to do. There are many other things that are going to be very important in managing multiple sclerosis for the rest of your life, but the first thing is to explore those different options.

What are the treatments? And we are going to discuss what are the different medicines that exist, the benefits and how effective they are, what are the side effects, what are the safety problems that other medical problems

we can induce with the use of medicines. And what is the expectation regarding efficacy? What are we going to get if we're going to put you on meds? What is the objective?

And we have to be very clear about this, because many times many individuals believe that because their blurred vision did not resolve, the medicine didn't work, and that is not the objective of treatment for multiple sclerosis. The objective, at this moment, with all the medicines that we have available, more than 20, 23, 24 at the moment, is very clear and refers to the fact that knowing that there is a risk of new injuries, again, the possibility of new problems and disability progression, we want to reduce the risk of that happening. That is what we can get with medicines. Reduce the risk of new relapses, new lesions on MRI or progression to deficits. It's not going to solve problems that already exist, so you shouldn't judge the effectiveness of treatment based on that. And when we understand that, we review the risks and the benefits of the treatment.

And you as a patient, and you as a relative of the patient, tell us what your likes are, what you don't like, what scares you, what is your level of risk. What is your plan regarding having children in the future? All these elements are going to be part of the conversation to talk about those values, those preferences, the options. And with all that, we make a decision.

This is the best step for you. That is the treatment that we are going to choose for you, because it is going to cover all the aspects that we have discussed. And after that, what? Obviously the process is not over, it is just beginning. We are going to continue from that point on a very judicious monitoring of the disease process and continue talking. It's not just me anymore. You are not alone. If the patient has new problems, if he has new symptoms, he has to raise his hand. We're going to talk later as the most effective way to do that, but he has to say, look, this is happening to me, listen to me, I don't know if this is a new problem or not, but I'm feeling this or that. Right?

And the doctor is going to have some very specific parameters of how he wants to continue monitoring the disease. How often are we going to do blood tests to assess the effects of the medicine? How often will we repeat the MRI to identify new lesions? How often are we going to see each other in the office to examine you and be able to talk? And again, open communication between the two is very important so that we can once again acquire benefits through a joint work process.

Julian. Has this been your experience? Have you had any difficulties with that process? What is your input in that regard?

### **Julian Gamboa:**

It is absolutely correct. It has been, as I said, a more or less difficult journey, but because, for example, my parents both worked in the Red Cross, so they both told me let's check what's up, since you don't have to do what your grandmother says, what the aunt says, you have to go check. So we went. But where I was at that time was not the best equipped place. We have one neurologist, I think, for all of Imperial County. So, it was very difficult to get an appointment. It took me months to get my first MRI and even longer to find out if it was vertigo, if it was sclerosis, if it was "6 nerve palsy." But it's definitely speaking with a lot of people and just trying to find out. I took two months off work and I just focused on my health to find out why I had so many appointments, I had to drive to various places because not everything was close to where I was. There was no ophthalmologist, they recommended me to another ophthalmologist in Palm Springs, so I had to take all day, and so on, until I found a doctor.

Like right now in Los Angeles, I have two doctors, Myra Chai who is my PCP, and Dr. Lilyana Amezcua, who is my neurologist, and I have had them for a year. And as I said, I have been super comfortable with them, they listen to me, everything I mention, unless it is so little, they consider it and I always see it in the notes that I ask for after I visit them. So it's like, that makes me feel more than... They listen to me. More than anything. Because once they told me there is no stupid question. And if it's true, because you don't know if that can work for you, as was said, it's another thing that helps the diagnosis to focus more on the diagnosis. So I tell all my doctors.

**Dr Gabriel Pardo:**

Absolutely, that is correct. In fact, just like other doctors are telling you, tell me anything, don't be shy about it, because you suddenly think it has nothing to do with it. Let us make the decision. Again, share through open dialogue, whether it has relevance or not. Sometimes things that you think have nothing to do with it are very important because they may be indicating that we are not controlling the process properly or the medicine is not working well. Sometimes it is the opposite. You are talking about things that have nothing to do with it. We still hear you, but we are going to direct the conversation a little to more important things. Right? And with that I think we can - go to the next, next slide - to talk a little bit about how to cultivate that relationship. So, because when cultivating a relationship we have to have some parameters as well that we have to understand.

The first thing is who is included in the healthcare team. You have to know your treatment team because if you know, then you will be able to take advantage of your team in an appropriate way and you will know who you should communicate with. These are very important things when you establish a relationship with your doctor so that we can have an adequate dynamic in the process of treating the disease.

Who is included in your health care team? Usually in managing multiple sclerosis you will be seeing a neurologist. That is the area of medicine that has the most specific knowledge for the management of multiple sclerosis, as such. We cannot forget that the patient with multiple sclerosis is a true total patient who may have other problems and other situations that also have to be handled appropriately. And that is why it is very important that all of us have a primary care physician. In the United States, a *primary care physician*, a *PCP*, because that is, and Julián told us that he has a PCP, because that is the person who will be the repository of all the patient's information. If the patient with multiple sclerosis also develops, I don't know, cholecystitis, your gallbladder becomes inflamed, well, the neurologist is not going to help you with that, don't even ask him, "why not?"

You have to go to the right person, but then someone has to be coordinating all that process and all those treatments. Having a *primary care physician*, a family doctor, is very important. But if we focus on multiple sclerosis, certainly a neurologist, in some cases you're going to have a neurologist who specializes in multiple sclerosis, and that can obviously give you some advantages in terms of access to newer knowledge, maybe access to treatments that they are experimenting with, clinical studies, that kind of thing, and suddenly you have a slightly more multidisciplinary team.

I don't want to say that a general neurologist who manages multiple sclerosis can't then also have an integrated team, not necessarily in the same place, but have their connections so that we have a complete team. And when I talk about a management team, I mean that in addition to the neurologist, there are going to be other people who are going to be treating part of your disease, aspects of your disease that are going to be important to once again improve the final objective, the quality of life. Right?

Who else can be in that process? Usually in the doctor's office we will have a nurse, usually that nurse is going to be the person with whom you can communicate most easily, who is going to distribute the information within the medical office to see who is the right person to respond to the questions, who is going to be the person who writes a new prescription for your medicine that is running out, the person who is going to be in charge of doing all that. So, you know who that person is, because when you're communicating with the office you better know who the right person is for that.

And depending on the manifestations of your disease, you will have other specialists involved in management. Very frequently, for example, we have a physical therapist, a physiotherapist, because she will help us with the problem of balance, gait, walking, that kind of thing. You can also see a urologist, because bladder problems are not uncommon in multiple sclerosis. Many times your neurologist can handle them, but sometimes we need a little more knowledge and understanding of the process to handle it properly.

There may be other people, for example, specialists in pain management. Pain can be a manifestation of multiple sclerosis. It is something that was taboo for a long time, it was believed that multiple sclerosis did not

cause pain, it wasn't possible, as it wasn't possible because the lesions that we see in the brain, in the dorsal column cannot, as such, produce pain. Because the brain doesn't have pain receptors, even though that's where we feel pain, the brain itself doesn't have pain receptors. If I could stick my finger without having to go through the head itself inside the brain, I could scramble your brain and you wouldn't feel a thing. Nothing. Because there are no pain receptors. All injuries, it was believed, cannot produce pain. Obviously they can produce pain by many different mechanisms, which is not the focus of the conversation tonight, but sometimes we need to, if we can't, as neurologists, manage the pain process independently, you may have to go see a specialist in that area.

Then you will see, again, many people who will be important in your management, and knowing who they are will not only facilitate conversation, help, but also make the most of your visits. And that's the next aspect. How are you going to take advantage of your visit? How do you prepare for your visit? I think that when we are talking about shared decisions, which is the topic tonight, we have to learn, both you and us, to make the most of the time we have together.

It is a limited time. Ideally we would have all the time in the world, but we don't. So we have to be focused on being able to solve specific problems. Depending on the circumstances, there are doctors who can spend more time visiting with you and examining you and conversing and talking, others who are with a little more structured time constraints. But you have to come prepared for the visit and with respect to what the circumstances are.

We are going to talk a little more about that, some specific details ahead, but before you go to your visit you have to think, take some time to think about what your questions are, what your problems are. You have to "prioritize"... Is that a word, "prioritize?" Prioritize... put in order of importance what are the problems you want to solve. Because a lot of times, and this is unfortunate, I have patients come in for a visit and we start talking. What is bothering you? Do you have any questions? No. Okay. I start to ask how this is? How is the other thing? How is that going for you? Oh look. And a stream of problems. Oh really? And then the next one and another stream of problems, but you told me you didn't have a problem. That patient did not take time to think about what his problems are and so we are going to lose the opportunity to be able to focus a little more on the most important problems that have to be solved in that visit. Right?

And so if you're ready, and we're going to talk a little bit more specifically about that in a little bit, then you're going to get more out of your visit so that we can again give you the best treatment and get the best quality of life possible. And integrating the team to understand, to have that mutual understanding as we were discussing, is going to be very, very important. Any comments, Julián, in that regard?

### **Julian Gamboa:**

No, everything he said is fine, because I had two medical teams, one before I was diagnosed and another when I was diagnosed. The previous one was in my city where I was born, in Calexico, California. It's not adequate for this neurology stuff, but now I live in Los Angeles and now I have another team that is obviously more financed and more equipped for everything. So, the PCP thing, when I was in Calexico I didn't have a PCP, so I would arrive with my eye crossed like that, with a patch, and I went to the first doctor and I told him, do you know what this one has and I don't know what this one is. The doctor arrived, he said okay, labs will go in a month. I have the patch for a month. He's like, it's going to pass after a month. I came back and another doctor treated me and he didn't know anything about me, just what he read. We waited for those labs for another month, and I said, I don't know, I'm waiting all the time. No?

In Vargo, here as in Los Angeles, I have stayed with the same doctors and it has basically helped me as a patient to be more relaxed, when I ask what I need to ask them. I have a little notebook that I always have close to me, if it's not in my backpack, it's on my desk and it's whatever strange thing I feel, I write it down for the next time I see my doctor, I ask them how, like a "checklist," "Oh, you know what? Three days after I took my *Kesimpta*, I felt, like, a tingling in my finger. Is it normal?" And they tell me "No" - well, let's see, that's what you have to do. No? So that way I am no longer scared that it is something more serious and I am relieved of any concern I have.

## **Dr Gabriel Pardo:**

Okay, look, I tell my patients the way I recommend we do it, it's that, that they make a list, that they write it down so that we do not forget it. So that we can then, and bring two copies, one for them and one for me. They keep one and I keep another... So, I can see what it is and I check... We talk about this, we talk about this, we talk about this. We may not have the answers to everything, I may not have the right answer, but then he's going to start a research process to figure it out. Right?

So come, preparing for the visit is very important and start thinking. We often waste a lot of time. What medicine are you taking? "Ah doctor, well, that red cap you sent me I take it every other day" But, what red cap? "Well, the tiny one" I'm not going to know.

Nothing, no idea. TRUE? So it's the other. Bring an updated list of your medicines with a concentration on both milligrams and frequency so you don't forget, and you don't have to ask "well, can I call my aunt María to go to the bathroom and tell me my medicines?" We waste time. Right? Let's take advantage of the time, and to take advantage of the time we have to be prepared. So that's very, very important.

With that we can go to the next slide. Yahaira is ready to make a *poll* with our attendees regarding... Next slide, - I think we are going to talk about self-advocacy, when self-advocacy is important, which we've been talking about a little bit already. I think to answer that, and for the benefit of time, ¡Self-advocacy is important all the time! All the time. Every visit, in between visits. You have to keep raising your hand and saying "but look, this is happening to me" Yes, and what do you do if they ignore you, raise your hand again in a very subtle way, "but doctor, I'm still worried about this problem. What will be happening to me?" And if you don't have a proper answer, if it doesn't satisfy you, then ask again. Speak differently, but don't let them not answer you. It is important. And sometimes there are no answers, but being told there is no answer because a, b, and c, and what are we going to do to find an answer. Right? I think we are going to go to the next slide. Self-advocacy we are talking about specifically. Why is it important with multiple sclerosis? Due to the fact that it is unpredictable, that it is multifaceted, that it presents itself in a very different way, because we do not know if this new symptom is or is not. You have to talk, you have to ask, you have to say.

Involving family and friends is super important, their support is super important. In addition to bringing things written down and knowing the answers to the questions we are asking, sometimes as patients, because there are so many things and the words are scientific, we do not understand what they told us. Right? If you have another person there who is taking notes or paying attention and who can ask other questions, the benefit of the visit is magnified. So I always recommend that you come with a relative, a trusted friend who can obviously be aware of all the details that are going to be discussed during the visit. Because we're going to talk about a lot of things, about the bladder and sexual health and a lot of other things. So don't bring someone you're going to be embarrassed to talk about these things, because we have to be honest and open. Right? But bring someone to help you through that process.

And what do you do when the healthcare provider refuses to listen to your opinion? Whoa whoa whoa whoa! That is an important question. I already told you a little about the fact that you should not let it go. You have to be respectful, true, but I think that when you tell your doctor, your healthcare professional, that you still have a concern or question, that you feel that it has not been answered, that you didn't get a response, I think that obviously opens up the dialogue again, if there is enough time, you can return to the office for another visit to address this problem only, if it is a more complex problem. If there is no time, that's fine, but we can visit next week, in two weeks so we can talk or discuss other forms of communication we can use.

And that is something very important that we did not discuss at the beginning. When we talk about getting to know your healthcare team, it is the question of how you prefer that we communicate when I am not here in the office. What is the ideal way? I pick up the phone, I call them or they have an online patient portal that I can post questions or email - which I don't recommend because it's not private. But there are many forms of communication. But ask how they want you to communicate with the office, with the doctor's office. That way,

we understand well what your process is. So self-advocacy is very important, understanding what the problem is and, again, with some responses, understanding why there is no response. Okay, next slide.

This is where, Yahaira, we have a little bit of time so that we can incorporate the comments that are being made, that are being filled in the chat and specifically about the role that shared decision-making has had in the ability to keep up with your care plan.

**Yahaira Rivera:**

Yes. So at this point we would like to know the experience of the participants who are part of the audience. If you want to write your comments in the chat. What role has shared decision-making played in your ability as a patient to follow, be faithful to, and be consistent with your plan of care? And while the audience writes their comments, Julián, would you want to share your experience?

**Julian Gamboa:**

Of course. It's been interesting because when I was diagnosed with, with,... well, it's so crazy, but... basically, they thought I had *6 nerve palsy*, I went and told my sponsor who is a retired doctor, I have a drooping eye and he said "Did they check your myelin?" And I said no, how do you do that? And he told me you have to get an MRI. So I had to go to my ophthalmologist and tell him we need to get an MRI just to make sure it's *6 nerve palsy*. And he was like, Oh, well, if we could, we should. We did an MRI, they found lesions and he said, Ok, we need to do a Spinal Tap.

And that's my cautionary tale. I am overweight and they did a *Spinal Tap* with pure X-ray. So what happens, it's a very small needle to a very small place, and if you're overweight, there's a lot where they have to insert the needle. Then they did the *Spinal Tap* and no fluid came out with the X-ray, and it touched several nerves. Awful. Then later the doctor told me, tomorrow, we'll do it again, but with a CT Scan.

And I went home walking very badly. I came back the next day. We did it, but in three days I couldn't get out of bed. So I had an operation, this, a discectomy, a bunch of things, and they already gave me my MRI and they told me, do you know what your diagnosis is? You have MS, you have to learn to walk again. I was in bed for two months. And now that I got this new medical equipment, it was very interesting to me, because as Dr. Pardo was saying, I went to my first consultation with Dr. Liliana, who said let's make your plans, these are your options.

Doctor Liliana told me that I would be able to choose either pills or an injection every month, or a transfusion every six months and I don't remember which others, but I think she told me three. Whereas the previous neurologist had told me you have to come and we are going to give you a transfusion every six months and you will be here for about six hours. And I said no, I don't like that idea, I prefer to feel bad every month. Right? And it also became more interesting to me when I went in with Dr. Liliana and we heard the plan and I, my mother, began to say, Ok, the pills, because of the surgery, I had been taking many pills, I have to take care of my... *liver*. Is that it?

**Dr Gabriel Pardo:**

It's correct.

**Julian Gamboa:**

I have to take care of my liver. It's the pills, they won't do. The transfusion, due to my job, I don't want to be there for six hours every six months. I said I don't like it. But if it has to be done, it has to be done. But the third option is that a small package arrives and every month I inject myself and that's it. I said, well, that one is better. And me and my mom said okay, maybe that one, and my dad, who surprised me a lot, but he's already a few years older, told me "But your eyesight is fine now, why are you going to continue taking the treatment?" And I said, it's just that this is life, there is no cure, it can alleviate a little, but it is very interesting to see how many people think about your health and all the factors that if you are not informed... Who knows, maybe if I would never have gone with my mom or dad, I would have said, oh, well I'm fine now. Why do I need to spend, why do I need to buy these things. While, when I went with my mom, my mom asked a bunch of other things

that I wouldn't have thought of, like what activities she can do. Can he lift heavy things, can he do this, or this. Can he do the *second dose del vaccine*, what things can he do. I am vaccinated, but that's another thing. Right? And that's very interesting just to see so many possibilities and so many ways of thinking and how this affects your relationship with your doctor.

**Dr Gabriel Pardo:**

Correct. *Next slide*, next slide - because that's what we're going to talk about, give you three examples of what we've been talking about. The first thing is differences in decision making. The first doctor said, this is it, and he "*blindsided*" you, like in English, right, like what are we talking about? The second person gave you options and discussed with you why, and you may have decided to do the same infusion every six months, but you would have a different confidence in the decision. It was not imposed. Right? It was shared. And that is the fact. That is what we are talking about here. That is the difference. Second, your mother came, she asked other questions, another set of ears to understand what is happening. And third, many people do not understand what is happening with the illness. That is why I wanted to talk at the beginning about the fact that it is a lifelong disease. The fact that your eye has improved does not mean that the disease is gone. Right? So it's very important. So that process gave us some excellent examples, what we've been talking about. This part that you have to be an active part in developing the plan that works for you. It is what we are talking about.

We have also discussed the challenges, because the most important thing, in addition to starting a treatment plan that is right for you, is that you maintain it in the long-term, right? Adherence to the treatment, because we can come up with a treatment, take all this time and effort to make a decision. But, if you don't adhere to it, it's useless. The medicine in the refrigerator. Nothing. Nothing. Right? So it is very important that we have good adherence and everything that is conducive to having confidence in medicine, that you have an open communication process with your doctors so that, if there is a problem, you can speak with them and solve the problem and not say, oh, I don't take this because I scratch my nose every time I take it. Ah, wait a minute, we can come up with a solution for that. Right? So it is very important that we do that. And we can go to the next slide. *Next slide*.

Those questions for you, you can put them in the chat. And if we are coming to the end here soon, we can then talk about these issues, but you can put them in the chat. We can go to the next slide. Talk about the challenges that you have adhering to treatment. *Next slide*.

**Yahaira Rivera:**

Dr. Pardo, I want to share with you one of the participants told us at the beginning of the talk that she had a treatment, everything was going very well, she had a good team, but her doctor is no longer there, so now she is in the process of having her treatment interrupted because she has not been able to find another person, another provider who will continue treatment and listen to her and respect her opinions as before. So that goes, it is related to our next question, right, which was about the challenges that some of the patients encounter and that is why the treatment is interrupted.

Another participant shares that she heard you speak in New York in a talk you gave years ago and that's how she learned more about multiple sclerosis, and that thanks to the support of her family and the support of her doctors and the shared input, she has been able to achieve true well-being and add quality of life. Then she encourages other participants to share other challenges they have had, as well as the ones Julián shared with us.

**Dr Gabriel Pardo:**

And I want to tell that person who wrote that I remember that conversation very well, that talk that I think took place in New York more than ten years ago, at least ten years ago, because it was very well attended, first of all, and I remember that we played a game at the end, that when we were in the question and answer session and people stood up to ask, I began to guess where they were from, based only on the accent. Right? Oh, you're Puerto Rican, or you're Dominican, or you're Mexican, or you're from Chile. Right? And I think I guessed almost all of them right, so I remember very well that visit to New York.

Okay. So in talking about the professionals with your doctor, we've talked about that. I think we can go to the next slide. *Next one.* How can we improve adherence, we've been talking about this. I think we have some more time for questions. We have a few minutes left. We have talked about this, reiterate communication, an open dialogue. Support. You have to seek support not only from your own health professionals, but from your family, your friends, your nucleus. They have to understand the disease, they have to understand that it's not that you're lazy, but that you have multiple sclerosis fatigue. "Ah, but you look so good!" Right, that's such a common comment. "But come on, you look good, but look, you're fine" and they don't understand what's going on inside. I feel how they say "*the procession goes inside,*" that is an expression in some parts of Latin America, they say that. I remember my grandmother saying "Oh no, do you think I'm okay?" But the procession goes inside, because the procession goes inside. And then, obviously, it is important that the people who are close to you understand and give you their support.

A continuous, long-term, lifelong evaluation process. Flexibility, conceptual flexibility, with flexibility of time, flexibility in decision-making, but with knowledge of why the decisions are made and your active participation, which is the result of a collaboration, of a process of open collaboration between all the participants in your health team. *Next slide.* The next slide. And Yahaira, we'll go back to you to reflect towards the end of the presentation.

### **Yahaira Rivera:**

Perfect. Thank you very much Dr. Pardo and Julián. It has been a talk with a lot of information, truly, many topics to cover, very important for our community. And so we are going to dedicate the few last minutes to questions and answers before closing the seminar. One of the questions that I know we already talked about tonight, but I think it's one of the most important, when the patient doesn't feel like they're being listened to. Many questions are related to that topic. "I tell my doctor what I want, what are my values, what are the personal things that I should share." But there are doctors who may be on another page. They are not understanding what the patient wants. So what can we do? What can we say to these people who are in this situation?

### **Dr Gabriel Pardo:**

Yes, it's obviously a major problem, right, because then we're not going to have a good relationship that will lead to good results. We've been speaking during the talk about some strategies to do that. I think that one important thing that we have discussed is to bring the written questions with two copies so that at the end of the visit we can say, Oh, doctor, do you mind if we see if we have already answered everything? And if not, then ask again, could you explain a little more about this or what is the plan about the other thing, do you want us to do another visit. If you're pressed for time, let's talk about this another time. But don't say, Oh, well no, no, he didn't tell me. Because no, it's your health, it's your life. But by God, who else is going to advocate for you if not yourself. Right?

So, you have to do it. And sometimes, sometimes, like any other relationship, like in marriages, sometimes you have to go to divorce, if it didn't work, it didn't work. If there are doctors who do not listen to you, if there are doctors who do not want to answer the questions or if you feel any other discomfort in the relationship, you have to...you have to go to someone else. Ideally, obviously, the relationship should work just like a marriage. We are going to a *Counselor*. Let's see if we can improve it, let's talk. But if it doesn't work out, well we get divorced and I get another one. Right? there is not a *Tinder* for doctors, but you're able to talk to other people about it in the multiple sclerosis community. Find someone you are satisfied with, find a good team. They listen to you, there is adequate communication, who do you communicate with in the office. Then you start talking to the other people in the community to see who can be a person and a health team that best suits your needs, your characteristics, your desires.

### **Julian Gamboa:**

Yes, I was just going to add that too, if it doesn't work, it doesn't work. So when I was with my previous medical team, I didn't feel like they listened to me very much and many of the conversations I had with my parents were

that if you're not satisfied in this hospital, what other clinic can work? So, I came to Los Angeles, but I was already thinking about, okay, I don't feel heard, so I'll go to a place where they do listen to me.

**Dr Gabriel Pardo:**

Correct.

**Yahaira Rivera:**

I definitely believe that with what you just said you answered several of the questions, because they were related to that topic. So it's important to get that, that health provider to listen to you, someone with whom you feel confident. And one last question that also summarizes several of the topics we discussed - What things are important, even if they are very personal, what things are important for a patient to share with their doctor? And I mean, for example, religion, values, traditions that could benefit or also interrupt treatment.

**Dr Gabriel Pardo:**

Ah, that is a very important question and there is an answer that is either long or very short. The short answer is everything. Everything that you think is important, relevant to your management, you have to say. Don't keep secrets. Secrets are not good. Secrets are not good, and especially because they can then result in providing a health system that is not, does not adapt to your needs, and if it does not adapt to your needs, then we are not doing the right thing.

Obviously there are sensitive issues. Obviously it depends on the circumstances, obviously it depends on the moment, what process we are in, in the management of the disease, both important factors. But again, the short answer is everything, everything you think can affect your health, everything you think can affect your relationship, everything you think can affect a positive outcome and improve quality of life has to be discussed.

**Julian Gamboa:**

Yeah. My mother, being a nurse, the first thing she said to me when I started this whole hospital process, she told me "there are no strange questions for doctors, they have seen everything." Then she told me if you think you're going to be the first to ask him things about X, they've already asked him and he has an answer. So that did help me a lot, although once I was with my mom talking to my doctor and when I wanted to ask a very personal thing, I just said it in English because my mom didn't understand, but everyone has already asked everything.

**Dr Gabriel Pardo:**

Yes, that's it. That's it.

**Yahaira Rivera:**

Perfect, thank you very much. We can move on to the next slide. I thank Dr. Pardo again for sharing his expertise, experience and wisdom with all of us. And to you, Julián, for sharing your testimony, truly. Within our community I think that's one of our favorite ways that we learn, by sharing our testimony. There are many questions, many comments. I ask the audience that if you have any questions, you can send us an email and I can send it to Dr. Pardo and we will contact you.

This concludes our talk for tonight. Once again Julián, Doctor Pardo, thank you very much for being here with us, thanks to our dear audience, for supporting us, for being here learning. And don't forget to fill out our survey to let us know what you thought, what you learned, and also to give us suggestions. I also invite you to visit our web page that is on the screen, to send us an email or to contact our telephone line to continue learning more about the available resources. And also know that this program was recorded and within the next few weeks you will be able to access it again, watch it again, share it with a family member or even with your doctor to continue learning together. We hope you find that team of medical providers who listen to you, who make you feel good so that your treatment is beneficial and adds quality of life. On behalf of the Multiple Sclerosis Association of America, thank you very much for participating and we wish you all a nice evening. Until next time. Bye bye.

**Julian Gamboa:**

Thank you.

**Dr Gabriel Pardo:**

Good night everyone.