Voces y Avances:
MS Research in Our Communities

Presented by:

Lilyana Amezcua, MD

Yahaira Rivera:
Hello, everyone. Good evening and welcome. *Bienvenidos*. We are so glad you could join MSAA's live webinar - ***Voces y Avances: MS Research in Our Communities*** presented by MS specialist and our dear friend, Dr. Lilyana Amezcua. In honor of National Hispanic Heritage Month and as part of MSAA's, Hispanic and Latinx initiatives, we are excited to share this important conversation with you tonight. This program is made possible thanks to the generosity of our sponsors, Genentech, Novartis, and Sanofi. My name is Yahaira Rivera, and I'm the Senior Director of Health Education for MSAA, and I'm honored to be your host for this important conversation. And now I would like to give you a brief overview of who we are and the programs and services we offer to the MS community nationwide.

MSAA is a national nonprofit organization dedicated to improving lives today through vital services and support. Our services include a national toll free helpline providing services in English and Spanish, equipment and cooling distribution programs to support mobility, safety, wellness and heat sensitivity, educational initiatives and publications to keep you informed about the latest in MS care, and we also provide digital tools, an online community forum, information and resources in English and Spanish, and much more. To learn more about our programs and services, please visit our website - mymsaa.org. And we want to make sure that you stay connected and you're not missing out on important events, so please visit our website, sign up to receive email updates, you can also follow us on social media, and now if you text MSAA to the number 75101, you'll get MS related news, updates about our upcoming programs and events, and also different ways to support the MS community right on your phone. So don't miss out and stay connected with us.

And now let's go over together some reminders and housekeeping items. During tonight's program, you are welcome to submit your questions using the Q&A. We'll do our best to revisit some questions during the Q&A after the presentation. And please know that close captions are available so you can choose to view them in English or Spanish by selecting the CC button in your toolbar in your Zoom screen. And tonight's webinar is being recorded and will be available as an on-demand video on our video library within the next couple of weeks. And as usual, at the end of the program, you are going to have access to a brief survey. We appreciate your feedback and always welcome your suggestions, so please let us know what you think about tonight's program.

This is our disclaimer. This program is for educational and informational purposes only and does not constitute any formal recommendations. If you have specific questions about your diagnosis or your treatment, we always recommend that you go back and have conversations with your providers.

And now please join me in welcoming Dr. Lilyana Amezcua. She's an Associate Professor of Neurology and Division Chief of Neuroimmunology and Multiple Sclerosis at the Keck School of Medicine at USC. She's the founder and lead researcher of the Alliance of Research in Hispanic MS. They're studying how MS affects Hispanic and Latino populations. Dr. Amezcua. is recognized nationally and internationally for her leadership and advocacy in the MS care and research, and she also serves as a co-chair of MSAA's Hispanic and Latinx Advisory Board. Dr. Amezcua we're so happy and truly honored to have you here with us tonight. We, in advance, thank you for your dedication and this presentation and we're looking forward to learning with you. *Bienvenida*.

Dr. Lilyana Amezcua:

Muchísimas gracias. Thank you so much. Really a pleasure to be here with you and really grateful for the MSAA and all the support that they give to us and our MS patients and the community. And so let me share my screen. Great. All right. So let's get started. And today's presentation is called Voces y Avances in the MS Hispanic community. And so my goal is to just go overview of what is MS, how is MS diagnosed, some of the importance of treatment and advances, and specific aspects of MS and how it affects the Hispanic community, and then leave you with some thoughts as to what can you do, or your community do, to help all of those affected with MS.

So what is MS, or in Spanish, also known as esclerosis multiple? So, MS is a disease of the central nervous system. And when we are talking about the central nervous system, we're talking about the brain, the optic nerves, and spinal cord. And what happens is that we understand that there is inflammation, neurodegeneration that is caused by demyelination, in terms of the nerve. And here you can see a really, just, rough picture of what these nerve neurons look like and there's damage to what we call the myelin sheath. And this leads to various symptoms that can be seen in MS, which includes, obviously, visual disturbances, walking difficulties, sensory symptoms, pain, bladder problems and cognitive dysfunction. And over the years, there has been tremendous advances. And probably many of you, if you have been called, "what type of MS may I have," and, you know, the old categories - relapsing remitting progressive MS, whether secondary or primary. But we've come to understand that there are also pre-symptomatic phases, of which there is a lot of research now being focused. And within the pre-symptomatic phase, there are spaces known as prodromal MS. And this has to do with symptoms that lead patients to seek care 5 to 10 years before the onset of MS. And some of these symptoms are not necessarily related to any neurological symptoms. They may include GI disturbances. So, these are part of what we call the prodromal phase.

Of course, many of you may hear of radiological isolated syndrome, (RIS). And this was termed to indicate that there is an MRI that looks abnormal and very much looks like MS and meets the criteria, but there has not been a demyelinating event that has occurred. And here you can see here in the relapsing phase where you have relapses and periods of quiet, but there is also a new sort of term that we are using, which is relapse associated worsening, or RAW, which is basically describing worsening related as part of a recent inflammatory event. Within the progressive phase, we've now come to understand that there are individuals, too, that are suffering or demonstrating evidence of what we call PIRA, which is progression independent of

relapse activity. And so all of these are leading us to basically try to focus on the biological aspects of the disease, to better understand neurological disability over time.

So what causes MS? Well, there are a number of risk factors that we have come to understand. We know that there is a genetic interplay with environmental triggers, and some of that relates to the fact that we understand that MS, if there is a relative or family history, there may be a higher risk of MS. For example, we've come to understand that the risk is 3 to 5 times greater if you have a first degree relative. When we're talking about a first degree relative, we are talking about a parent, a sibling, a child. So for example, just like I mentioned, it is 2 to 5% for a sibling, which is much higher than actually a parent. The risk increases to 25% to 30% in identical twins. But that in a way leaves us with 70% of it not being genetic, if we're thinking about an identical twin. Important aspect about admixed populations, or, for example, Hispanic people, we understand that a lot of the genetic risk variants that have been found in white and predominantly European populations are shared. And this is important, because there is likely more alike than difference. And this is also so for black communities.

In respect to environmental triggers, of course, there is a vitamin D deficiency story where there's a lack of vitamin D that has been linked to an increase in MS risk. Importantly, what is much more a higher risk is [sunlight] exposure. So insufficient sunlight correlates with a higher MS prevalence in all populations, actually. And this has been shown both for Hispanic, black, and white populations. There is also a link with cigarette smoking. So if you're smoking, stop smoking. Smoking is identified as a significant risk factor, and this has also been associated with a progression of MS. EBV is probably the highest risk factor or has the highest magnitude. And in many cases, a new study suggests that this could actually be the cause. And still a little controversy, but nevertheless, it has probably one of the strongest associations, particularly with EBV infection and the development of MS. In particular, for Hispanic communities, CMV may be protected. So really understanding the interplay of these genetic environmental factors is very crucial in us trying to address MS risk and prevention and actually leading to a cure of MS.

So, what else do we know about MS in Hispanic communities? And I have to say that more than 15 years ago we knew less, and so for the aspects of prevalence, basically, it is understood that it is lower than white people, but nevertheless very much increasing in the last several years. So when we're talking about prevalence, we're talking about all existing cases. So, in this case, I am putting up data related to multiple studies that have shown that, for example, if you look at the United States for white people, there are 374 individuals with MS per 100,000. And this was a prevalence that was calculated for 2010. When you look at the Hispanic population for that same period, it is 161 for every 100,000. A second study used age standardization, and they found that close to 70 per 100,000 for 2022, this is a slightly different to, for example, the neighboring country of Mexico, which is 13 per 100,000, while for Puerto Rico it is much higher.

The differences between these three countries is the fact that Puerto Rico, for example, if we consider this age standardized to be highest, is that they have a registry, which means that every case that is diagnosed with MS goes into a registry that is island based. And so you have a very good estimation, as opposed to Mexico which does not. And there are many regions in Mexico that MS is unlikely to be diagnosed or calculated. For the United States, of course, this was based on a lot of medical claims, and so really, perhaps, leaving out a large population. Nevertheless, even though it's almost half the amount of individuals of white background, Hispanic individuals with MS is expected to rise due to just the population growth that we have seen in the last 15 years.

So what else do we know about MS in the Hispanic community? And a lot of this has come through the Alliance of Research on Hispanic MS, followed by multiple other studies conducted nationwide. And so one of the things that we observe across different cohorts is that Hispanic people often develop MS symptoms younger than non-Hispanic white people. So this means that they are presenting or having symptoms of MS at a younger age. And particularly in one of our studies, we also noted that those that were U.S. born tended to have an earlier onset than those who immigrated later. And so below, you can see in the table different studies noting the mean age at symptom onset as well as the mean age at diagnosis. In one of our studies, we noted that Hispanic people were about 2 to 3 years younger than white people and most of them are around that average. In terms of also the diagnosis, they appear to also be younger in many of the cohorts, despite noting that they also experienced diagnostic delays.

So let's talk about diagnostic delays. Actually, in 2001, when the MS diagnostic criteria were first introduced, the average time to receive an MS diagnosis was four years. And this, I'm talking about in general, not necessarily the Hispanic population. In 2017, the criteria changed and the average time to diagnosis was reduced by 75%. So basically when we now see a patient with MS, we're really hoping to diagnose after their symptoms within the year, and that is much more common. Nevertheless, we still see and experience a lot of diagnostic delays in populations that have not been well represented or understood. Right? And so, an average for symptom onset to diagnosis takes much longer. And in one of our studies, again like I mentioned, it took about more than a year longer compared to individuals of white background. So these diagnostic delays could be the result of multiple things.

And one recent study that was presented in the past several months at AAN, at the American Academy of Neurology, was able to shed light on some of these barriers. And so it appears that, for example, Hispanic individuals wait significantly longer to see a neurologist after their first symptom. So, for example, they found 15 months compared to two months for white people. There is also a longer time to diagnosis. And we've seen that before. Right? But that was an older study and you would expect it now to be shorter. But we are talking about 2025, where it's still noting that there's a median delay of 23 months compared to 13 months for non-Hispanic white patients. So almost double. There is also... this will mean longer time to treatment.

So some of the underlying causes behind these observations may be, of course, it may be symptom awareness, health care access barriers, which we can talk about, social and cultural factors, and provider bias. So, for example, symptom awareness - well, if the community is not knowing what MS is, they may not understand that some numbness that comes and goes may be something for someone to go check it out. In terms of healthcare access, there maybe also a barrier here where an individual may not have access to a neurologist, whether because of geographically where they're situated, but also in respect to having insurance. And then there's the social and cultural factors, which may actually be even just, you know, what that symptom may represent or aspects of, well, you know, it goes away. Or, if I do go and complain about a sensory symptom, I may be considered a weak person. And then there's the aspect of provider bias. So it's not just in the patient and the community, but it is the fact that for many years it was only thought that MS happened in white populations. And so there may be a bias in the diagnosing MS, but also in delaying MS, because they are looking for other causes to explain those white spots in the brain.

So, MS diagnosis, of course, is not an easy thing. It is a complicated diagnosis to make and not every physician may be versed in doing so. Nevertheless, there has been a criteria that has been created many years ago, first developed in 2001, and it has been updated over several years, the last one being in 2017. And just yesterday, publishing the most recent one, for now,

which will be called McDonald Criteria 2024. And this criteria is the critical tool in MS diagnosis. It is basically what is telling us what we need in order to make a diagnosis, what needs to, basically, “check mark” in order for us to provide that diagnosis. And so it enables providers to balance the need of an accurate diagnosis and avoid obviously making errors, with the goal ultimately to give that diagnosis early so we can start effective treatment.

And so, in MS, the most important thing is that there has to be MRI lesions. In the past, at one moment, there was, and this was because our MRIs were not strong enough, in terms of strength, that perhaps you might have heard, Oh, MS can happen without white spots. Well, no, they... not at this moment. MS typically will have lesions. And again, the strength of the magnet is important. And the typical lesions that we always see and use for MS, where, for example, in “A” we see what we call a pariventricular lesion. This is a white spot. And then in “B” is what we call a juxtacortical lesion. And in “E” we are seeing a spinal cord lesion. And in “D” we're seeing one in what we call the brainstem. And these are typical lesions where commonly they are associated particularly “D” and “E” to some form of presentation, whether it's a spinal cord syndrome, a brainstem syndrome. And then “A” and “B” may correspond to multiple different symptoms.

One of the things that is also common is that many people, white or whatever background you may be, may experience what we call an optic neuritis at presentation. So, what we're saying, is as a first demyelinating event. And one of our earlier studies suggested that higher optic neuritis presentation is found in Hispanic groups, particularly those of Mexican background compared to others. And reported rates can range from 32 to 54% compared to 14 to 20%. But we also found across these studies was that there may be some genetic, ancestral contributors to this observation. So, for example, we found that while Western U.S. Hispanics have a high rate of optic neuritis as their first symptom, that eastern U.S. Hispanics, predominantly Caribbean, were less likely to present with optic neuritis. And when we did genetic, ancestral assessments, we found that Native American ancestry was linked to having a higher frequency of optic neuritis as initial first symptom, but also associated with a younger age of MS onset. And this is really important. So this is telling us some unique aspect of some Hispanic groups, where if optic neuritis as a site in the diagnostic criteria is basically not being used, we might be missing individuals early on where we could diagnose MS.

So we went ahead and did a study to try to see if we could improve diagnostic performance of the McDonald 2017 criteria, where we added optic neuritis as a site to be considered. So I went over four areas that you could have lesions. But then we added the optic nerve, and we found that we could improve the diagnostic performance of the criteria. So this meant that we could actually diagnose nine additional patients much earlier. And this study was helpful in also contributing to the new diagnostic criteria, which again, we are celebrating it because it just came out yesterday. And so now the new criteria is basically changing how we diagnose. The MS diagnostic criteria is now updated and now will include, which I will go over, additional things. It will include the ability to use additional MRI markers. It will also include other CSF. So for those that know and got a lumbar puncture to look for oligoclonal bands, now you can look for other things. And we can also use to show optic nerve as a site. So if you're presenting with optic neuritis and you have a lesion in the optic nerve, we can now look at it and visualize these using MRI, whether it's an orbit or optical coherence tomography, which is a ultrasound of the optic nerve, or what we call visual evoked potential test. And and so all of these things and tools are being used to try to diagnose MS early.

So adding the optic nerve will now serve as the fifth anatomical location, like I mentioned, using these different tools. And you can basically fulfill the criteria and be called right away MS if you

have two of the five regions that I mentioned. So if you have a spinal cord lesion and an optic nerve lesion and nothing else explains it, you can meet the criteria for having MS. So this makes a big... it contributes greatly. So now the new MRI lesions that can speed up diagnosis is, like I mentioned, in (A) the periventricular lesion, the (B) juxtacortical. The (C) will now include optic nerve lesion, (D) the brainstem, (E) the spinal cord lesion. And they added two additional lesions that have been central in our understanding about multiple sclerosis, which includes the paramagnetic rim lesions, or also, basically, contributing to that smoldering MS, in a way, and central vein sign, which is just telling us that there is exactly what it is - there's a central vein where, in pathology, we understand that that's where the demyelination occurs around it. And this central vein and paramagnetic rim lesions is adding more specificity to our ability to diagnose MS. Of course, many of you may be asking, like, well I was diagnosed with MS, do I have these lesions? You don't need them, but they can basically... they accessorize or they can actually help if you're not meeting a certain criteria. So they're not required. But they are there to assist the diagnosis.

In respect to the lumbar puncture, basically oligoclonal bands, for those that have oligoclonal bands, of course, we can still use that to assist in the diagnosis, but there's been an additional measure that is also a biomarker, which is called kappa free light change, which are little segments of antibodies produced, what we call B cells, and they are much easier to calculate. And so I think this might be something good for areas where oligoclonal bands take time and are difficult to do. And so you will be able to diagnose MS, for example, if you have the lesions that I talked about. So, dissemination and space, so different lesions in your MRI, and you have these oligoclonal bands or you can use kappa free light chain in order to, again, diagnose MS.

And why are we so concentrated on these criteria, right? Well, because we want to make sure that we have the accurate diagnosis. Right? That we are not diagnosing somebody with MS that actually just has vascular disease, but also because we want to prevent the disease from, you know, poor clinical outcomes. Right? So disability, and obviously just prevent disease burden. So the extended period, before, many years ago, we would have to wait for one attack and then wait for a second attack in order to diagnose. And between that time could be many, many years, which would then lead to having more MRI lesions. So we actually had to wait for added MRI lesions, right, to meet the diagnosis. And in between, you know, of course, people could develop disability and progress. And so, again, we are with the goal of preventing diagnostic delays to prevent overall poor outcomes.

So what is the importance of early treatment? Well, we know it is key in treating MS. And so our goal is that when we diagnose, we want to initiate therapy as soon as possible, as soon as it is confirmed. And now with this evolving criteria, this is certainly going to be much sooner. And we already have many, much data from different clinical trials and observational studies and real world studies that we can improve long term outcomes and reduce disease progression. We also understand that if an individual is not doing well and we see breakthrough, whether it's relapses or a combination with radiological changes, that we need to change therapy, maybe, too, but also examine what side effects are there. And nowadays we have over 20 disease modifying therapies. And so certainly it requires a shared decision approach, right, where both the patient and physician are on the same page, at least, and try to reach an agreement to the best treatment for the individual that is going to have the same objective of delaying disability and poor outcome. Of course, there are also individuals that we are now looking, you know, we stop treatment. Of course, these are all unique situations that always require a thorough discussion between the patient and the health care provider. And every case is unique and distinct. And so that's why you see the whole diversity and different treatments across different people.

But one thing, that does come up frequently is, well, were these populations represented in clinical trials? Like I mentioned, there's over 20 clinical trials. And, in a lot of these clinical trials, there was a lack, a small number of participation from either Hispanic or black people or Asian people. And now we understand that this is important for us to know if this treatment would have the same efficacy as what we see in the past with white people, or, in general, moving forward to make sure that different populations are being represented so we know that it generalizes to all.

So here is just a snippet of phase 3 clinical trials in the past, where you can see across, for example, Alemtuzumab, 43 patients were of black, African background as opposed to Dimethyl Fumarate, there was representation of a combination of black, Hispanic and Asian people, and Dimethyl Fumarate, for another one, as well. In the S1P receptors, for example, Fingolimod, you see that there was some representation of Hispanic and African background. And then much older studies, Interferon and Natalizumab (Tysabri) were much smaller number, primarily African background. And for the Ocrelizumab, which was... African descent was only 72. Of course, there is a phase 4 clinical trial which is known as CHIMES, which is basically dedicated to understanding the effectiveness of OCREVUS among black and Hispanic people, and that has also been very successful. But overall, the main findings is that many of these treatments appear to be as effective as in white populations. Nevertheless, moving forward, instead of trying to guess if it is, there just should be good representation. Participation, of course, we need participation from the populations, meaning wanting to know, to see if the treatments work as well.

So what are the needs and priorities of the Hispanic MS community? And so even just based on what I've just been talking about, you can see that there is a number of challenges that they face, primarily this issue of a delayed diagnosis. And so this was a recent survey that was done by the MSAA, and it did show that, you know, again, 45.5% experienced a delayed diagnosis. And I wonder if the data is suggesting, yes, there are, you know, it can be more than three years or five years where there is a lag in diagnosis, there can be a range, of course, a huge range, for those that were diagnosed a long time ago. I've seen delayed diagnosis up to ten years. And so our goal is to shorten that and bring it down to within a year. Right? Within a year. And, but part of the delayed diagnosis, of course, we understand has to do with having access to health care. And there is some studies that have suggested that access to an MS specialist is an issue, where 30 to 40% either black or Hispanic people are less likely to have access to an MS specialist. So this may be related to the fact that where either where they live or it’s an issue of type of insurance, or maybe not knowing that they could be referred to a neurologist. And so this is important. Other things that they face is affordability of treatment. And I would also add access, and that may be access to health care. Or, do they have access equally to all the highly effective therapies? And this may also be an issue related to where they are seen and where are they taken care of, which if it includes public assistance type of insurance, they may not be having access to the most, to the more newer treatments and highly efficacious treatments. Nevertheless, there are studies suggesting that at least providing access to rituximab may provide less of a health disparity. There's also, other things such as lack of understanding and social support, emotional and mental health challenges, which probably has to do with community support and understanding what the disease, needs are.

So, what can we do to assist those with MS and their communities? And, of course, we need to prevent diagnostic delays, but part of that diagnostic delay, if we go back to the patient needs to be aware that there are symptoms that require some evaluation. And one of my friends and colleagues, Dr. Jaime Imitola from University of Connecticut, published this recently on MSJ,

which is basically creating a framework that is bilingual for early MS awareness. And we're hoping that this will give light in terms of letting us know does the community recognize MS. And this is known as “Visibly or Visible.” And basically it is describing, for example, VISI is a painful loss of vision or also known... or loss of color vision. And this has to do with optic neuritis. Those are symptoms of optic neuritis. The “B” is for balance. So balance can also be an issue. And this may be related to a brain stem lesion. There is also the limb weakness and numbness which may have to do with the spinal cord lesion. And then the “Y” is just to remind ourselves that MS commonly starts in your 20s or 30s. And so we're really talking about the young adult. VISIBLE in Spanish. Same thing. *Desi pérdida de visión dolorosa, pérdida de visión en color, “B” pérdida de balance, yellow, “L” pérdida de locomoción o sensación en las piernas, “E” edad joven... edad adulto... Joven adulto.* And all of this is really important. So we're trying to tailor health literacy programs to the different communities involved that are affected with MS. By doing so, we can enhance MS care for all of the communities that are needing to have more attention and are being affected by these issues.

Additional things that we can do is, again, I just talked about a new criteria. And is this new criteria going to be as sensitive and specific as we have published that it is? Is it true that it's going to be more accurate, or are we going to have additional issues because the individuals do not have good access to the MRI or to the specialist, or the specialist is not really aware of the criteria? Then, they may not be basically using the criteria correctly. But what we do need is greater participation and research from these communities, because right now a lot of our data is based off of what we know about MS in past communities. Right? Predominantly white populations. But now that we know that MS affects these communities, in order to know what their MS journey is, what those outcomes are, what causes those poor outcomes, we need to have participation. Otherwise we're just guessing. Right? And so, and then the other one is more at the physician health system level. Right? And also personal. Right? We want to know the barriers so we can develop interventions, tools that are specific to target and develop programs to address them.

So how can we participate? Well, the participation starts with your local community, with the MSAA, and... but also if you want to participate in research, we have the Alliance for Research in Hispanic MS, which, a lot of the foundational data, I do attribute this to our collaborative effort with this alliance. And so you can go to ARHMS.org, sign up for the newsletter, contact our coordinators so you can be part of this registry, or at least for us to tell you where you can go. And I look forward to answering the different questions and your concerns. Thank you.

Yahaira Rivera:
Thank you, Dr. Amezcua, for sharing such important information with our community. I think that we are super excited and blessed that you just shared with us information about the updates in the criteria and research updates and how it relates to the Hispanic community. We're happy and fortunate to have access to this information. So now we do have some questions from the audience. And some of them I believe that you have answered throughout the presentation, but I think it's important to revisit. Has there been studies on what medication works best for Hispanic males since they deal with the more severe case of MS?

Dr. Lilyana Amezcua:
It's a very good question. No, I don't think there has been any studies that have focused primarily in the outcome of a male Hispanic. But we do understand, in general, and for many years, that males could possibly be doing worse. But what we do think is that perhaps the male is coming to awareness of their symptoms and diagnosis at a much later time. Nevertheless, in terms of looking at specific treatments that would be better, that has not been done. But

certainly we believe probably that high efficacy medications should be considered if there is disability or high disease burden from the beginning. And I would urge, definitely, for that to happen. Now, moving forward, there is a lot of interest. Right? And one is woman's health, but there probably should also be looking at male, you know, the way males do as well. And so that could be something that we could probably include in our initiatives to try to better understand the barriers encountered, stratified by, looking at sex and, you know, and gender and how that might affect different outcomes.

Yahaira Rivera:
Thank you for that. Our next question is about trust. How can the community start trusting clinical trials, and how can they know about these opportunities?

Dr. Lilyana Amezcua:
Absolutely. Well, I mean, I think, you know, the conversation has to start, and one of the things that we've, you know, are trying to understand, you know, in the past there was atrocities that happened in these communities in the way that they were recruited, with not providing the right informed consent, or not being told of what their data would be doing, what we would be doing with data. I think we've come a long way, where there is, you know, even within the staff, there has to be a very specific training that requires that we understand whether it's how we recruit, how we deliver the informed consent to these communities, and that there is sharing of the information and understanding before anybody can take that signature for granted. So there are a lot of things that are in place now where we do need to, you know, be able to try to get that trust. But it's also about talking and having that conversation, and whether it's, you know, it is you and thinking about participating but still being hesitant, being able to communicate that hesitancy is important because we will only get to understand that better if you ask that question.

There is many different ways of involvement, as well in research. It may be very low risk, which starts with the registry, and maybe that's a way of getting your feet wet, with, you know, joining a registry. And then, of course, I would say the highest, sort of, way of participating, it is clinical trials. Right? Because in many cases, in a clinical trial, we, you know, it has to be the right fit for you. Where are you in the disease that you are wanting to explore a new treatment? What options do you have, what options you do not have. And and then the aspect of placebo versus control, you know, placebo control and getting a treatment. And so, that is important to be able to know what is, what what might be those benefits and risks regarding those treatments, even if you're receiving, a placebo, so meaning no treatment at all, there is some data that suggests you still can note an improvement, even just by the fact that you are being seen much more often and much more detailed. And so, there's all of this that needs to happen. But from us as providers and as researchers, it should be our job to be able to invite everyone, regardless of the background or state of their disease and invite them to participate in clinical trials, if that is something that's fitting, you know, at that moment for that patient.

Yahaira Rivera:
Thank you. That was very powerful. And I think that's so important. And if you're listening and you have a provider that has never told you anything about how to be involved in clinical trials or research, start by asking questions and having that initiative of asking the questions, looking for resources. And if you don't know where to start, MSAA is here to help. So our next question, Dr. Amezcua, is, it says: I was diagnosed with MS 23 years ago and I have been on my MS therapy without interruptions since then. I'm 70 years old and my MS is stable. When may I discontinue my MS therapy?

Dr. Lilyana Amezcua:
Oh, that's a really good question. And like I mentioned, every case is unique. So I'm not going to say to go ahead and discontinue based on this information. But commonly, you know, we take into consideration the DISCOMS, but we also take into consideration the history and story of each individual. And, you know, for instance, is the DISCOMS used, you know, five years of clinical stability, three years of stability and MRI. And when we say stable, no new symptoms, no worsening symptoms, no new lesions on MRI, and stability in MS treatment for at least that time and patients could, you know, they were randomized to discontinue or not. And in fact, actually, even right now there is an initiative to try to, How do we communicate the results of DISCOMS, where there was some observation of some individuals that did break through. And, despite that, you know, the study being what we call a negative study, there is individuals that do. And so I would say take that story to your physician, talk about it, and then he or she can basically see if this will be right for you. But I will tell you, when you do discontinue, there needs to be a protocol that, you know, that follows, which may include, repeating an MRI at six months after the discontinuation.

Yahaira Rivera:
Thank you. And a question that just came in, it says: I believe Dr. Amezcua mentioned that there can be signs of MS years before onset of symptoms. Is there a push for this information to be shared with doctors like general practitioners?

Dr. Lilyana Amezcua:
Very good question. Yes, we are referring to the prodrome phase of MS, where the large databases, such as in Canada, have shown that there is increase of healthcare utilization. So, meaning - patients are going to the doctor for symptoms such as, oh, I have some stomach issues or I have some fatigue, I have some concerns, and not amounting to MS. And when they compare that to controls, they found that those that were eventually diagnosed with MS were the ones that were utilizing more of those services. And so now there's a push to try to say, it's like, okay, can we teach, you know, or sort of make... create awareness of this prodrome to primary care physicians? If there's a patient that keeps on coming in as a young adult and you can't find a reason for these symptoms, would it make sense to do an MRI? Let's say. I'm just saying an MRI. But perhaps for those with a family history, it could. And so I think there's still a controversy as to what we need to come together as a community, researchers and MS specialists, to say, do we start looking at this prodromal phase to try to see if we should go ahead, should we do MRIs, should we do other investigations without burdening, you know, and creating a disaster? Right? Because if everybody with these symptoms starts getting that, that's not going to happen. But so, but yes, there is already plans to do something. Some sort of that.

Yahaira Rivera:
Definitely. That would be wonderful. And also as a community, the more we know about the symptoms, the more we can advocate, especially those who are going to those visits and everything comes out normal, or they don't have answers, just to ask, what about MS? What about if I have MS? Right? The more we know, the more we can understand. And that awareness is crucial. So our next question is: It’s hard to choose between so many MS medications, especially for newly diagnosed. In your opinion, what are the best types of treatments for Hispanics? And I know that is a hard question. We can be in the general idea. Right?

Dr. Lilyana Amezcua:
Of course. And the general idea, and there's a reason why over 20 DMTs, disease modifying therapies, exist and none of them are marked X. Right? Because there could be a place for all of these in any of our MS patients. And I, for one, I use everything. But whether there is evidence that only certain ones work in the Hispanic community, there isn't. And so right now, what we do know is who participated in clinical trials. Right? Who participated in clinical trials where there has been more participation or perhaps more dedication, whether it is from the sponsor doing the study to say, hey, I'm going to specifically look at these communities to see how MS on this treatment behaves. And there has been. Right? And more recently, there's a lot more interest in that, because we want to also be sure that we are not, you know, obviously, harming and thus far right now, at least, you know, we can think about ocrelizumab and the CHIMES study where basically it is showing high efficacy, efficacy very similar to the pivotal trial. And this was published. Right? Where we have presented and shown very similar efficacy and trajectories. And so that means it likely works as well, even though it was not a phase 3 clinical trial, similar to these other studies and the other treatments that I showed.

And so, all of this is in a way, as a physician, is putting trust in the fact that these therapies are likely to work as well in these individuals. There are studies that I will say are ongoing to better understand the immunology of what's happening. And that is a study that we currently have between USC, UT Southwestern, and Cornell, where we're basically looking at the immune function, whether it's how B-cells behave, and other cells that are part of... that are important to MS. And, this is important because, you know, our immune system is not necessarily reflective of what it is, you know, what's happening today, but it is reflective of all the ways it can be [linked] to our ancestors. Right? And so that's where the population differences may be observed.

Yahaira Rivera:
That’s such great news. Right? That the voices are being heard, that there are studies going on. And so that's always good. And speaking about answers, our next question reads: My ancestors and I never heard about MS before. Why does MS seem more common now in Latinos and Hispanic than in the past?

Dr. Lilyana Amezcua:
It is very interesting. Right? So one is - has it been because there is now more risk factors that were encountered by this population? It's hard to know, because recently, now there is much more understanding that these populations can also have MS, and maybe the fact that we were just not... the lack of awareness, they were not coming and being diagnosed or seen. I'll tell you personally, culturally, when I was younger, if somebody had some sort of a disability, or *la abuelita* or *la tia* had a cane, you didn't really ask why. So, you know, it makes you wonder whether it was MA or something else. But, you know, there was less awareness of that. Commonly you will, however, find an autoimmune sort of signature in many of these patients, and so I think more so, even also for the African-American community, is that it's just been the fact that we believed, where there was provider bias, that MS just didn't occur in these populations. And then as soon as we created more awareness and studies started coming out, we now have greater understanding that these patients, that these communities are affected. That's why the prevalence of Mexico being so low, which is so border and then so high here, might be just an issue of more awareness, more neurologists, more health care access. And you have MS.

Yahaira Rivera:

Definitely. And speaking about access, we did receive a couple of questions about where to find resources in Spanish. There are resources in Spanish. And again, you can start by visiting our website. We do have information in both English and Spanish. And make sure that you find trusted resources where you can... that are research based and that they can help you not only to be more informed, but also to, when you have conversations with your providers, are you empowered to do that? And, the more you know, the better health outcomes in the long run. Right?

So we have time for one more question, Dr. Amezcua. How far are the clinical trials in developing a medicine or to solve and rebuild the myelin? That's an important question. So I know there's some research going on, right?

Dr. Lilyana Amezcua:
Yes, absolutely. Well, there's new categories of treatments that are being investigated, that are focused on whether we call it regeneration or remyelination. Right? And so, we're looking forward now to these new faces where there is Car-T or something else. Right? And then there's a potential of a new therapy that we'll hear soon for BTKi's, whether that is contributing to remyelination by seeing some benefit in what we call these paramagnetic rim lesions. And I think that is really exciting. And, I know, I understand that it's been approved in the UK. And so we're just hoping to hear more here. But yeah, there's new categories that are up and coming and looking forward to that. So if anything, I think in the next five years, there'll be a new generation of treatments that will be out.

Yahaira Rivera:
Thank you for that, Dr. Amezcua. And before we bring closure to our webinar, I would like to give you the space to just give a word of advice or any last words that you would like to share with our Hispanic community tonight.

Dr. Lilyana Amezcua:
Absolutely. Well, I mean, it is, you know, if you can participate, whether it's research, whether in your community, whether it's to create awareness or participate in registry based studies or ask questions about what you would like to be involved in, I think that's important. If you don't raise a voice, we won't know and we will continue, you know, working as what we think we should do. Also, part of addressing these, you know, the barriers that I mentioned does necessitate that you be involved because, again, we want them to be effective and target what your needs are, not what my needs are.

Yahaira Rivera:
Thank you so much, Dr. Amezcua. Once again, we are truly grateful for your time, your expertise, for everything that you do for our community, for being a voice, and for making sure that there is research going on incorporating the Hispanic and Latino communities. Thank you for everything that you do and for your work with us.

To everyone joining us today, thank you for participating. Thank you for your questions. And as we close, please remember three things: stay connected, stay informed, and make your voice heard in the MS research. You're part of this community and we appreciate you. So we hope that you found this webinar helpful and informative. This webinar was recorded and will be available on our website within the next couple of weeks. So you can always go back, watch over again and share with family members and care-partners. Please take a minute to complete the survey and let us know what you thought about our program and your learning experience.

We appreciate your feedback. On behalf of MSAA, thank you, have a wonderful evening, and happy National Hispanic Heritage Month. *Buenos Noches!*