

# MULTIPLE SCLEROSIS ESCLEROSIS MÚLTIPLE IN THE LATINX COMMUNITY



ADVISORY BOARD FINDINGS, PROPOSED STRATEGIES, AND SOLUTIONS  
TO ADDRESS UNMET NEEDS IN THE LATINX MS COMMUNITY

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*This program is made possible through the generous support of Bristol Myers Squibb, Genentech and Janssen.*



# INTRODUCTION

The Latinx community is the largest ethnic group in America, although some members prefer to identify according to country of origin or with the term Hispanic. Just as identification may vary from person to person, living with multiple sclerosis (MS) impacts each member of the Latinx community uniquely.

According to US census data, the Latinx population is growing. With MS affecting an estimated 2.9 people per 100,000 in the United States, a higher proportion of the US Latinx population is likely to be diagnosed with MS compared with some populations in some countries of ancestral origin.[1] There is also a difference in the onset of symptoms, which tend to appear in the US Latinx community at a younger age compared with non-Hispanic whites.[1] Latinx people living with MS also report higher rates of optic neuritis and ambulatory disability when compared with non-Hispanic Whites with MS.[1]

These and other symptoms—which can be invisible to those not experiencing them—may be further exacerbated by environmental influences. Cultural factors such as family values and health beliefs, access to care challenges, health literacy, and language barriers all play a role in how people of Latin American origin may experience MS progression and treatment, which affects health outcomes and overall quality of life.

## THE VISION

To gain a deeper understanding of how the US Latinx community experiences and understands MS—in collaboration with Impact Education, LLC—MSAA convened two virtual Advisory Board meetings spanning nearly 8 hours with 16 participants from the MS healthcare professional and patient advocacy communities, including Latinx physicians who specialize in MS and people living with MS. The group discussed areas where support is lacking and various solutions for closing educational gaps. This white paper summarizes key discoveries of the 2021 Advisory Board with a positive outlook on MS-related well-being for members of the Latinx community.



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*While respecting their privacy we would also like to recognize the people living with MS and their care partners who also participate as invaluable members of the Hispanic and Latinx Advisory Board.*

# LOOKING AT LANGUAGE: WHAT'S IN A NAME

## Multiple Sclerosis Esclerosis Múltiple In the **Latinx** Community

### Outreach & Understanding

A primary focus of the Hispanic/Latinx Advisory Board meetings was to promote discussion of preferred overarching terms that would represent the most inclusive language for Americans of Latin American descent in the context of MS support and outreach. While many people identify by their country of origin—for example, Colombian, Cuban, Mexican, or Puerto Rican—as a group, opinions vary about how to inclusively represent this population as a whole to create the most effective support and outreach. Latino (or Latina) seems to be preferred among members of younger generations, while Hispanic (Hispano, or “a person descended from Spanish settlers”) is a more traditionally used term, the Advisory Board noted. Latinx is a more modern, gender inclusive term that is widely accepted, but not commonly used in daily vernacular.

***“Yet another mission for an MS patient: You’re your best advocate. You have to be in control of it all.” -  
Community Advocate***

The Advisory Board also discussed the terms “MS” (abbreviation for multiple sclerosis) and “EM” (abbreviation for esclerosis múltiple). Provider participants widely agreed that when speaking Spanish to patients or more formally in a conference or educational setting, they use the term esclerosis múltiple, but not “EM” for short. “MS,” instead, is widely accepted in both English- and Spanish-speaking communities. The physicians, who were bilingual, noted that in the clinical setting, they tend to follow a patient’s lead regarding which language is used in their discussions. For purposes of this white paper summary, the abbreviation “MS” is applied.



# LINKING EDUCATION & OUTCOMES

*“We need to educate better on the importance of treatment.”*  
*Lilyana Amezcua, MD, MS, FAAN*

It's critical to examine the specifics of MS messaging since effective education is linked to improved outcomes. A lack of information about MS can negatively impact patient outcomes. For instance, many patients suffer through symptoms in silence for months or years, leading to delays in diagnoses. Hesitancy remains in seeking care, initiating therapy, as well as in remaining adherent to therapy once under a physician's care. The Advisory Board members unanimously agreed that patient and community education are vital to MS identification and management.

There are many goals of improved MS education in the Latinx community. First, greater awareness of MS as a disease may help patients acknowledge their symptoms and appreciate the importance of seeking care. The earlier MS is diagnosed, the earlier the person living with MS and their care provider are able to create a treatment plan that can prevent worsening disability. Through education, people living with MS and their care communities can learn the importance of seeking care, as well as the value of self-advocacy. Since MS is a highly individualized disease, people living with MS and their care communities must understand and communicate their own experiences to their doctors for effective conversations about treatment goals and efficacy.

When people living with MS and their care providers are adequately managing disease course and symptoms, patients will start to feel better. Overtime though, this sense of improved health and wellness can contribute to a loss of interest in treatment for some people. In reality, a specific treatment or combination of therapies—which may include medication, diet, exercise, and other maintenance strategies—is actually what's keeping the symptoms under control. Any lapse in treatment can have a lifelong impact.



# LINKING EDUCATION & OUTCOMES CONTINUED

From an educational perspective, it is essential to deliver the message that appropriate use of a disease-modifying therapy (DMT\*) in conjunction with comprehensive mental and physical wellness strategies keeps MS under control. The Advisory Board also conveyed the importance of understanding what a full treatment team may look like, including a neurologist specializing in MS, general practitioner, and optometrist/ophthalmologist.

Also, part of the educational effort toward self-advocacy in the Latinx community includes empowering people living with MS to speak up about their own care. For example, if a person's needs aren't being met by the current provider, switching physicians is a valid and empowering response. Similarly, if a specific therapy is not generating an intended or adequate response, persons must know that they can discuss this with their care communities and doctors and switch therapies. Empowerment through education and shared decision-making helps people living with MS achieve optimal outcomes.

***“Knowing that you have the ability to switch doctors is magnificent.”***

***– Community Advocate***

In addition to the online sources for patient education noted above, infographics and other short-form content delivered via e-blast or physical materials through trusted community resources could be helpful. This would include various forms of audio-visual messaging. MSAA regularly provides patient education opportunities that feature a physician and numerous patients who would receive disease-related education with the opportunity to ask questions, though physicians cannot provide specific medical advice in educational settings. Brief video testimonials from people living with MS on the importance of adhering to drug therapy is also an effective educational support tool.

*\* DMTs are long-term treatments to slow multiple sclerosis disease activity and progression. There are currently more than 20 DMTs approved by the U.S. Food and Drug Administration (FDA) for relapsing MS in adults.\**

# LINKING EDUCATION & OUTCOMES CONTINUED

Since the treatment of MS in both the Latinx community and general population is so individualized, it's important that people living with MS keep an open line of communication with their physician teams to share symptoms, concerns, and possible solutions for relief. Due to the multifaceted nature of MS, treatment must be patient-centered and well-maintained. Physicians and community health services can best support people living with MS by underscoring the importance of a comprehensive care approach.

***“We believe that a holistic approach in the treatment of MS is absolutely necessary if we want good outcomes and to improve the quality of life of our patients.”***  
***– Gabriel Pardo, MD***

Finally, educational and support efforts shouldn't be directed only toward people living with MS, but also to the family and friends in the Latinx community who support them. Since so many of the symptoms of MS are “invisible,” community advocates said in Advisory Board meetings that loved ones did not understand their illness or even believe they were unwell. People living with MS who are experiencing fatigue or dizziness, for example, may be mistakenly deemed as lazy or unengaged. As “fine” as someone may seem, it takes a lot of work, attention, and compliance to appear “normal,” one community advocate explained. Educational efforts must convey this message along with basic facts about MS for caregivers and the potential severity of this central nervous system disease.

***“This is a very hopeful time for our MS patients”***  
***- Rebecca Romero, MD***





# SPREADING THE MESSAGE

*“We wish they knew this  
(symptoms related to living with  
MS) wasn’t made up.”  
– Community Advocate*

In decades past, it was common to reach the Latinx MS community for educational and outreach purposes through radio and television, including channels like Telemundo.[2] Various forms of print media also have been used effectively. However, preferred means of gathering information have gradually transitioned away from these resources and toward Internet sources, videos, social media, and social networking channels. These include YouTube, TikTok, Instagram, Facebook, and Snapchat, to name a few.[2]

*“The more information patients have, the better  
conversations and relationships they have with their  
doctor...improving adherence.”*

*– Victor M. Rivera, MD, FAAN, Distinguished Emeritus Professor*

The working group reviewed existing MSAA offerings and partnerships for the Latinx MS community. Even with a variety of resources for the community and MS patients, there are still opportunities to effectively spread the word about this often-misunderstood disease.

The Advisory Board identified brevity as a key characteristic of effective MS messaging in these domains, noting that short videos—under 10 minutes—and visual communications using infographics and other images work best to convey important information about the disease. By providing this material in snippets, patients and their families can more effectively digest key facts and figures.



# SPREADING THE MESSAGE CONTINUED

The Advisory Board also discussed language barriers associated with MS-related messaging in the Latinx community. These hurdles must be consistently addressed to facilitate self-advocacy and health literacy—both of which impact patient outcomes. Language use is certainly individualized and depends on demographics, birthplace of origin, education, and numerous other factors. These hurdles must be consistently addressed to facilitate self-advocacy and health literacy—both of which impact patient outcomes.

***“We’re going to walk the walk together”  
- Carlos Ramirez-Calderon, MD***

Due to strong familial ties in the community, media is often consumed in a multigenerational setting, where younger generations tend to communicate more often in English and older generations communicate primarily in Spanish.[2] Therefore, the Advisory Board surmised that all communications, programming, and materials, should be distributed in both Spanish and English. One working group physician noted, however, that a pamphlet or handout with content in two languages will be twice as long, making it more intimidating to read. Having separate materials in each language is generally preferred.

In addition, the working group recommended that video/audio on important MS-related topics for the Latinx community be produced in both Spanish and English or delivered in Spanish with English subtitles. In general, individuals prefer to have medical information presented in their primary language.

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# ZEROING IN ON PROVIDERS

*“We need to be better about establishing community engagement, and that includes neurologists.” – Lilyana Amezcua, MD*

People living with MS in the Latinx community rely on their physicians to guide diagnoses and treatment plans. However, neurologists and non-neurologist providers may lack the expertise to make definitive diagnoses or appropriate referrals to specialists. Delayed diagnoses are more common in the African American and Latinx communities. And these community members are 30% to 40% less likely to have a neurologist as their provider.

Keep in mind, MS is a complex disease and is challenging to diagnose. There is no single test to confirm it, and numerous other conditions and diseases have to be ruled out amid a range of evolving symptoms. To support the community, provider education that enhances disease awareness, recognition, and timely diagnosis is imperative. Providers also must have a clear understanding of the roles played by various providers—including ophthalmologists, primary care physicians, ER physicians, OBGYNs, social workers, and case managers—and their responsibilities in the diagnosis and treatment of MS.

Educational support for non-neurologist providers can come in the form of webcasts and presentations at various non-neurology specialist meetings, medical society gatherings, and trade organization symposia. Less formally, peer-to-peer forums or a network for non-neurologist providers to consult with neurologists on the appropriate management of patients living with MS would also enable additional resources for the Latinx MS community.

It is imperative that MS symptoms are not missed or attributed to another condition, disease, or disorder. General practitioners may not recognize MS symptoms. Even general neurologists may not be up-to-date on current research and symptom-specific MS treatment development. For providers not specializing in MS treatment, it is very difficult to keep up with rapid advancements in the field.

# RETHINKING OUTREACH FOR IMPROVED ACCESS

Since the experience of living with MS can be challenging, people living with MS in the Latinx community typically benefit from regular connection with other people living with MS and their physicians. Specialists can provide a wealth of knowledge on the disease itself and the available treatments, while people living with MS can share commonalities of symptoms and experiences.

*Some physician specialists noted during the Advisory Board meetings that they, too, learn from their patients and that mutual participation via open discussion is critical to outcomes success.*

Latinx people living with MS generally trust information delivered by physicians and the community continues to seek opportunities for peer-to-peer interaction via in-person social settings in addition to support meetings that have occurred virtually as a result of COVID-19 distancing protocols.

Community advocates suggest various ways to cover important issues relating to MS, including webcasts to reach broad audiences of the Latinx MS community; smaller local meetings that include food and music; and in-person educational sessions that feature speakers presenting on current research and treatments, navigating insurance coverage and related assistance to reduce the expense of medication, psychological difficulties stemming from the disease, disability and employment law, and lifestyle alterations that help with symptom management.

Campaigns that bring general community awareness to MS regarding its diverse array of symptoms and the impact on patient well-being will help reduce stigma. For example, a provider in the Advisory Board meeting shared that a patient's loved one recently asked about the disease being contagious. Information dissemination can occur at "pop-up" events and through online media via webcasts that people living with MS can share with peers and loved ones.

# RETHINKING OUTREACH FOR IMPROVED ACCESS CONTINUED

These webcasts could also highlight MS stories from patients of Latin American descent, the group noted. A database of resources for the Latinx MS community—to be housed online or distributed in one-page communications on a local level—could also be an effective channel for educational support. Achieving a greater understanding of the disease within the Latinx community will equip family members, coworkers, neighbors, and friends to better support people living with MS and their care communities.

## COMMUNICATING COVID-19 INFORMATION

The COVID-19 pandemic has impacted members of the MS community at large and specifically the Latinx MS community. With concerns about contracting the virus and worsening symptoms, many members of the community have been fearful to venture outside of their homes. Some were uncertain if vaccinations would impact their treatment course and vice versa. Misinformation about vaccines and their general impact on the MS community is common and is spread through social media channels as well as by peers and family members. People living with MS and their family members require support in the form of education about COVID and vaccinations. They should also be encouraged to seek information from their providers about vaccination strategies based on their individual treatment plans.

To support this effort, educational programming aimed at both patients and providers in the Latinx community could include Q&A webcasts on COVID-19 vaccination in the Latinx MS community, a brief “fact vs. fiction” video on COVID-19 and MS, and infographics about vaccination distributed via e-blast through local MS community chapters.

# IN SUMMARY

We are grateful to the participants of the MSAA Advisory Board meetings who shared dialogue regarding unmet needs in the Latinx MS community. From a support perspective, providers and community advocates identified challenges that include language barriers, misinformation, stigmatization, and suboptimal treatment adherence, suggesting means for community-wide education to improve MS disease management and outcomes.

With the goal of reaching more patients, providers, and community members with clear and effective engagement, MSAA will enhance awareness of MS and create more opportunities for interactions that support positive outcomes in patients of Latin American descent.

***“We have made tremendous strides in the understanding of what MS is...and coming up with new treatment strategies that have, no doubt, revolutionized how we approach the management of MS.”***  
**– Gabriel Pardo, MD**

## REFERENCES

1. Amezcua L, Oksenberg JR, McCauley JL. MS in self-identified Hispanic/Latino individuals living in the US. *Multiple Sclerosis Journal – Experimental, Translational and Clinical*. 2017;3(3):205521731772510
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# MSAA MISSION STATEMENT

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