

On the rise



Diagnosis of MS is increasing among Latinos and Hispanics, and as awareness grows, treatment is improving.

by Vicky Uhland

When Nancy Wendirad was diagnosed with multiple sclerosis in 1992 at age 29, she was desperate to get more information about her disease.

“I remember how terrible I felt, like the whole world had fallen on top of me,” she says. “I just wanted to talk to someone to learn the ins and outs of living with MS.”

But Wendirad didn’t know anyone with MS. Born and raised in Mexico, she immigrated to La Salle, Colorado, with her family when she was 17 years old. No one in her family knew of any other relative who had the disease. In fact, they hadn’t even heard of MS until Wendirad was diagnosed. “My family members were asking, ‘What is the doctor saying you have?’” she remembers. “It was quite a fright, and all of us were devastated and alarmed.”

Wendirad was grateful when she discovered the National MS Society and could learn more about her disease. She became active in Society events, eventually becoming an MS Ambassador. “But I very seldom came across Hispanics at the programs I attended,” she says.

ngg_shortcode_0_placeholderAnd that hasn’t changed over the years. Wendirad works as a migrant education advocate for high school students in Fort Lupton, Colorado. Since this small town is 55 percent Hispanic, she makes sure to have a table full of English- and

Spanish-language MS literature at her school's yearly college community-resource fair. "But no one ever comes up to me and says, 'Oh, my mom has MS, or my uncle does,'" she says.

So Wendirad started investigating.

"I asked three different pharmaceutical companies if they had literature showing what percentage of people they treat for MS are Hispanic. They didn't know," she says. Thinking that maybe Latinos simply were not being diagnosed or treated on a consistent basis due to language and cultural issues, she volunteered to be an advocate for the companies' Hispanic patients. "They said they didn't have a need for that," she remembers. "That was a little disheartening."



Lilyana Amezcua, MD. Photo courtesy of Lilyana Amezcua, MD

Wendirad's experiences are not uncommon. For many years, doctors and scientists thought MS was rare in non-Caucasian populations. Consequently, research on how the disease affects Hispanics and Latinos is limited. According to Lilyana Amezcua, MD, assistant professor of neurology at the University of Southern California's Keck School of Medicine and a Society-funded researcher, there are fewer than 40 published studies focused on MS in Hispanic-Americans. Overall, research on both Hispanics and African-Americans accounts for less than 1 percent of all MS scientific literature.

That's rapidly changing, however. Dr. Amezcua is one of the founding members of the Alliance for Research in Hispanic MS (ARHMS), which aims to create partnerships between researchers and clinicians who care for Latinos with MS. More than a dozen studies have been published by ARHMS members in the last six years, and several more are underway.

MS: Coming to America?

These and other studies are finding rising rates of MS in Hispanics—particularly in first- and second-generation Americans.

“Doctors are telling us, ‘We didn’t use to see this disease [in the Latino population], but now we do,’” says Annette Langer-Gould, MD, PhD, a research scientist and neurologist with Kaiser Permanente in Pasadena, California. “Our research shows that 6 percent of Hispanics report a family history of MS, which is about half of what blacks and whites report. And Hispanics are more likely to report the disease in people of their generation, like a cousin, rather than an older relative.”

While there are still more questions than answers when it comes to Hispanics and MS, researchers are discovering that genetic ancestry and environmental factors are particularly important in determining which Latinos are more likely to get the disease, and how it progresses.

Cultural differences, language barriers, lack of access to quality medical care, and immigration issues also create roadblocks that can make treatment difficult or even unattainable for some Hispanics with MS. But concerted efforts by people living with MS, healthcare professionals, researchers and advocates are helping to improve diagnosis and treatment in Hispanics not only in the U.S., but also worldwide.

Defining a population

One of the major stumbling blocks to learning about MS in Hispanics is that there are different definitions of “Hispanic.” “We had quite a debate about whether we should use the word Hispanic or Latino in the ARHMS title,” says ARHMS founding member Jacob McCauley, PhD, director of the Center for Genome Technology within the John P. Hussman Institute for Human Genomics at the University of Miami.



Jacob McCauley, PhD. Photo

courtesy of Jacob McCauley,
PhD

For some, Hispanic and Latino are interchangeable. For others, Hispanic denotes people who originally came from Spain, while Latino is more representative of Latin American natives. Besides creating cultural questions, this lack of consensus on ethnic terminology can also cause problems with scientific research.

“In most studies, people self-identify as Hispanic or Latino. They can be white or black, with ancestors from Europe, Africa or elsewhere,” Dr. Amezcua says. To help clarify that disparity, she; McCauley; Angel Chinea, MD, of Puerto Rico University; Corey Ford, MD, of the University of Mexico; and Jorge Oksenberg, PhD, of the University of California at San Francisco recently began a Society-funded study that will examine a variety of factors in people with MS, including environmental elements, the presence of two or more chronic diseases, social and cultural practices—and genetics. The study will involve about 400 self-identified Hispanics or Latinos from Los Angeles, Miami, New Mexico and Puerto Rico. All participants will have been diagnosed with MS within the last two years and will be followed for two years. And each participant will undergo a blood test to determine his or her genetic background.

Previous studies have shown that genetic ancestry may help determine who is more likely to get MS and how severe the symptoms could be. For instance, says McCauley, MS has been shown to be rare in people living closer to the equator and more prevalent in Europeans. So does that mean that American Latinos of Caribbean ancestry, some of whom descended from enslaved people from Africa, are less likely to get MS than Mexican-Americans whose ancestors came from Spain or Latin America? Or, as McCauley puts it: “Is the genetic influence from Europeans really driving the fact that there’s MS in the Hispanic population?”

McCauley and Dr. Amezcua hope their current study will help answer that, and also shine some light on how genetic ancestry may affect the disease course in Hispanics with MS.

Different places, different symptoms

Several studies show that Hispanics with MS are more likely to have optic neuritis (an inflammation of the nerves that connect the eyes to the brain) than other ethnicities. But results for other symptoms vary.

A study by McCauley and his colleagues published in *Neuroepidemiology* in 2015 found that white Hispanics who said their ancestors came from the Caribbean were significantly younger at diagnosis and had more mobility impairment than non-Hispanic whites. And Dr. Langer-Gould’s 2014 study on MS in whites, blacks, Asians and Hispanics who were mainly Mexican-American reported similar results. Hispanics were, on average, between five and nine years younger than other ethnicities when they were diagnosed, according to her study, which was published in **Neurology** and the **Journal of Neurology**.



Jennifer Rios, diagnosed with MS in 2000, says that her diet and lifestyle factors seem to play a role in how she feels.

Age at diagnosis and severity of symptoms also appear to be influenced by a person's immigration status. A 2016 study co-authored by Dr. Amezcua and published in the *Journal of Child Neurology* found that Hispanics diagnosed with MS after age 18 had more severe disability than those diagnosed at earlier ages. But those born in the U.S. were less likely to have mobility issues. Dr. Amezcua's other research, published in 2015 in *Multiple Sclerosis and Related Disorders*, shows that Hispanics who immigrated after age 15 to the U.S. were older at diagnosis compared to those who immigrated at a younger age or were born in the U.S. They also had triple the risk of ambulatory disability (someone who is unable to walk or move without some type of aid) compared to those born in the U.S.

"This research argues strongly for environmental risk factors," says Dr. Amezcua. "In Hispanics, it appears to matter if you're U.S. born or non-U.S. born in terms of age of MS diagnosis and disease severity."

Living the American nightmare

Dr. Langer-Gould puts it more bluntly. "There's something about being in the U.S. that's affecting MS diagnoses in Hispanics," she says.

But no one's sure exactly what that is. Smoking is a risk factor for MS, but Hispanic-Americans smoke less than other ethnicities, she says. Hispanics do tend to have lower levels of vitamin D than other ethnicities, but Dr. Langer-Gould's MS Sunshine Study, published in 2016 in **Neurology**, found that lack of the vitamin doesn't seem to be a risk factor for MS in blacks or Hispanics. "Blacks have a vitamin D-binding protein that makes them use the vitamin more efficiently," she says.



Felisha González aseguró que el estrés de su trabajo y factores genéticos potenciales quizá hayan desempeñado un papel en su diagnóstico de esclerosis múltiple.

Foto cortesía de Felisha Gonzales

Partially because of their diets, Hispanics in the U.S. do tend to be more prone to metabolic syndrome and obesity, which is a risk factor for MS. Jennifer Rios, a Dearborn, Michigan, resident who was diagnosed with MS in 2000 at age 18, believes her fourth-generation American but “100 percent Mexican” family’s diet could possibly be a factor in the high number of MS and other autoimmune diseases among her relatives. Two of her paternal cousins have been diagnosed with MS in the last decade. Her aunt has lupus, and her grandmother had Alzheimer’s.

“My cousin says food is love, but we know Mexican food isn’t the best for us,” Rios says. “I’ve found that if I cut out dairy, fried food, red meat and flour tortillas, I feel better. But that’s changing everything I’ve ever known. It’s horrible when I go to a Mexican restaurant with my family and have to eat salad.”

Rios is a teacher in a Detroit middle school where most of the students are Hispanic. “We know diet contributes to diabetes, and diabetes testing is common at our school,” she says. “But there’s no awareness of MS.”

And as immigrants become more acculturated, they may adopt traditional American lifestyle factors that can also play a role in MS.

Modesto, California, resident Felisha Gonzalez believes she was in a “perfect storm” for MS when she was diagnosed in 2015 at age 28. “I was in a high-stress job, and I had had severe infections in the past.” She also has potential genetic risk factors—her mom, who is Caucasian, has MS. And her dad, who is a second-generation Mexican-American, has a cousin with MS. But she is aware that genes are only part of the equation when it comes to susceptibility to MS. “There may be more environmental factors than just your skin tone,” she

says.



Janice Maldonado, MD. Photo courtesy of Janice Maldonado, MD

Barriers to care

Quality healthcare is so important for the treatment of MS that Dr. Langer-Gould believes the disease progression in Hispanics is more likely due to disparities in care rather than ethnicity.

Migrant workers and their families, undocumented immigrants, and other Hispanics with poor or no health insurance rely on the county clinics in Southern California for healthcare, she says. But these patients are rarely seen by the same doctor, so there's little continuity of care and plenty of education gaps. There are often no infusion centers available for MS relapses. And some people with MS symptoms never even make it to the clinic because they have transportation problems, can't afford to take unpaid time off from work or don't have childcare.

"For our uninsured or underinsured patients, MS care is a complete disaster," Dr. Langer-Gould says.

When Janice Maldonado, MD, was on the faculty at the University of Miami, she helped care for indigent Hispanic patients at Jackson Memorial Hospital from 2003-15 and saw firsthand how delayed access to care worsened symptoms in people with MS. "It's not easy to get into specialty care, and new immigrants may not know how to maneuver the healthcare system," she says.

While drug companies help fund medication for people who don't have adequate health insurance, Dr. Langer-Gould says there's often no follow-up from clinic staff to see if their

patients are taking the medication. There's also very little data on which medications might work best for Hispanics.



Joseph Martinez, diagnosed with MS in 2008, notices that healthcare for migrant workers is more focused on immunizations, checkups and other basic healthcare rather than complex diseases like MS. Photo courtesy of Joseph Martinez

Wendirad says for Hispanics who are undocumented, “they have to be dying to go to the doctor.” And while there are clinics that offer medical care on a sliding scale and don’t require documentation, “sometimes they ask questions that may be a little intrusive, and people are afraid to answer.”

Joseph Martinez, an event planner in Commerce City Township, Michigan, who was diagnosed with MS in 2008, says his mother is involved in healthcare for migrant workers. “The focus is more on immunizations, checkups and other basic healthcare” rather than complex diseases like MS, he says.

While the Society and other groups now offer Spanish-language education materials about MS, Dr. Maldonado says that wasn’t the case a decade ago. And despite living in an area that has a large Hispanic population, Wendirad says she’s never seen information about MS in Spanish in any of the four neurologist offices she’s visited.

Dr. Langer-Gould notes there can also be trouble with Spanish-language translations or even cultural interpretations in educational materials or clinic intake forms. “You can’t just change the English to Spanish,” she says. “I’ve seen questions like ‘How often do you feel full of pep.’ My young Hispanic patients ask, ‘What is pep?’”

Cultural influencers

In a study published in May in the International Journal of MS Care, Dr. Amezcua and her team examined how other cultural factors affect MS diagnosis and treatment in Hispanics.

They found a distrust of traditional Western medical practices and more willingness to use alternative healing methods such as massage and herbal remedies like arnica, chamomile, turmeric and marijuana. Some traditional families believe in concepts like *susto*, in which the soul becomes frightened so much, it leaves the body. When it comes back, it creates disease.

“There’s also a fatalism based on Christian thought—that this is what God decided to give me as my cross to bear,” Dr. Amezcua says.

Clarissa Hidalgo, a yoga teacher in Merced, California, who was diagnosed with MS in 2010 at age 19, says her Mexican grandmother sometimes refers to her as “*pobre chica*,” or poor girl.



Clarissa Hidalgo, diagnosed with MS in 2010, says she faces challenges with her family members understanding her MS. Photo courtesy of Clarissa Hidalgo

“She wants people to take pity on me and recognize the disease is not my fault,” Hidalgo says. “Every night she tells me to pray and ask for my MS to be gone. I’m religious, but I don’t attribute my disease to that.”

Family is often important in Hispanic culture, and family members often want to learn about and participate in a relative’s MS treatment.

“I’m seeing my Hispanic patients get more involved in education,” Dr. Maldonado says. “They want to know all the details about their disease. They’ve often studied treatments and have very sophisticated questions.”

Part of this is due to extended outreach to Hispanics with MS through Spanish-language

publications, social media and support groups. But more can be done. Last year, Dr. Amezcua and her fellow researchers debuted a short film, "[Dentro de Mi](#)" ("Inside of Me") that's designed to portray the Hispanic MS experience through storytelling.

"Using tools like films have the potential to better illustrate the interplay between immigration, culture and health," she says. "And that can help promote MS awareness and self-care in patients, and cultural sensitivity in providers."

Vicky Uhland is a freelance editor and writer in Lafayette, Colorado.

A Spanish-speaking MS Navigator can be reached at 1-800-344-4867, Option 3. For information and resources in Spanish, visit [Esclerosis Múltiple](#).

Investigators are [recruiting Hispanics/Latinos with MS](#).