

Decoding MS

The Role Of Genetics In
Multiple Sclerosis Comes
Into Sharper Focus



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INFO CORNER

What is NARCOMS?

NARCOMS is a registry for people who have multiple sclerosis (MS). Registry participants complete two surveys each year to provide information about themselves and their experience living with MS. Data from these surveys is used in research studies and to help further our understanding of MS. Participation in the registry is voluntary, and responders' identity and privacy are carefully secured.

What is the goal of NARCOMS?

The NARCOMS Global MS Patient Registry helps to facilitate research about multiple sclerosis in North America and around the world. Collaboration between MS centers of excellence throughout the world helps to increase knowledge, improve clinical care, and enhance the quality of life for persons with MS.

How private is my information?

We will keep the information that you provide us private and confidential by storing your data in a secure database. All information will be used for research purposes only. We do not share any personally identifying information with any person or research institution. We follow all Federal (HIPAA) laws regarding confidentiality.

Not yet a NARCOMS participant?

Please contact us at
www.NARCOMS.org to enroll online.

Tell us your thoughts!

Have an idea? We would love to hear from you!
Send us your questions, comments,
and suggestions.

Email: MSRegistry@narcoms.org

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DIRECTOR'S LETTER

Dear NARCOMS Now Readers:

WE HOPE THAT YOU ARE ENJOYING the beginning of spring and look forward to your responses to the Spring 2024 Survey.

In this issue of *NARCOMS Now*, the Feature Focus examines how an individual's genes and their expression may shape disease occurrence, symptoms, and outcomes in people with multiple sclerosis (MS), and the role of the immune system in these processes. Genetics may be used to develop predict symptom severity. In the future, we hope that a better understanding of the relationship of genetics to disease outcomes will lead to new treatments.

In the Snapshot, we introduce the *NARCOMS Individual Data Report*, an analysis of your individual responses over your time as a participant in the NARCOMS Registry. The Report provides a visual summary of participant-reported disability, as well as physical and mental health status. We offer this report to all active members of NARCOMS Registry as recognition of your contributions to MS research.

In the MS News sections, we describe a recent study examining a link between bacteria in the gut and the risk of MS. In addition, we look at a study that describes the impact of genetic variation on the onset and severity of MS. Finally, we present a report of genetic elements that may influence the occurrence of Clinically Isolated Syndrome and MS.

We appreciate your participation in the NARCOMS registry and thank you for your continued effort and contribution to MS research! 🌐



Sincerely,

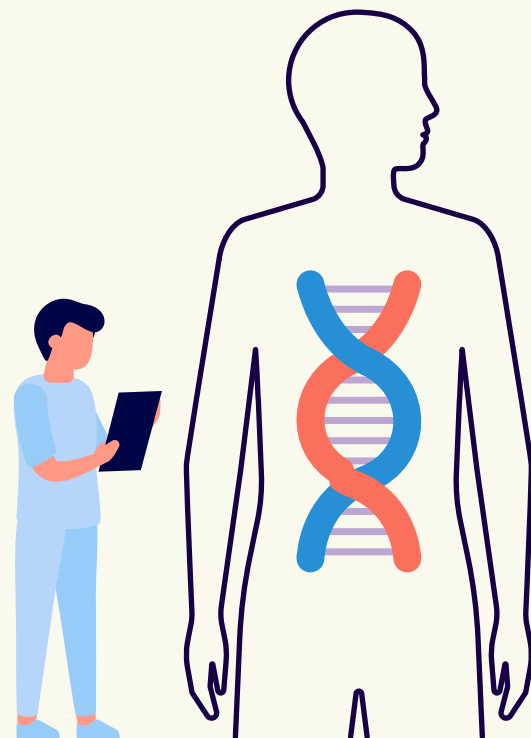
Ruth Ann Marrie, MD, PhD
Scientific Director, NARCOMS



DECODING MS: Genetics' Role In Multiple Sclerosis Comes Into Sharper Focus

As researchers zero in on the genetic triggers for multiple sclerosis, therapeutic advances loom on the horizon.

BY: MATT ALDERTON



LIKE A BARBIE DREAMHOUSE that parents might gift their young daughter for her birthday, or a piece of IKEA furniture that college students might purchase for their first apartment, all living things—from goldfish, geckos, and gorillas to ferns, flies, and finches—come with instructions that tell Mother Nature exactly how to assemble and operate them. Humans are no exception. Through the miracle of genetics, the cells that constitute the human body know precisely how to sequence themselves to give you green eyes or blue, blonde hair or brown, and lots of freckles or none.

Thanks to decades of research, scientists know that the human genome also plays a role in whether or not you develop multiple sclerosis (MS).

“It’s been known for about 40 years that genetics has an impact on multiple sclerosis risk,” said neuroimmunologist Vilija Jokubaitis, PhD, an associate professor and group head in the Department of Neuroscience at Monash University in Melbourne, Australia. “The main area within the human genome that’s been shown to associate with the risk of MS is the human leukocyte antigen region, or HLA region,

which is a really interesting region because it’s got a lot of genetic variation within it.”

According to Dr. Jokubaitis, the HLA region orchestrates the immune system. “Everybody’s immune system is slightly different. Some immune systems have advantages in some environments and disadvantages in other environments,” she continued. “Researchers found that there are some genetic signals within this region that determine how the immune system works, and they found one signal in particular that showed that people who carry a certain genetic variation are more at risk for autoimmunity in general and for multiple sclerosis specifically.”

Eventually, researchers studying the HLA region of the human genome concluded that individuals who carry the aforementioned genetic variation are three times more likely to develop MS compared to those who do not carry it. “That’s well and good. It tells us that our immune systems are responsible in part for our susceptibility to MS,” Dr. Jokubaitis said. “But that’s not the whole picture.”

For now, at least, the whole picture remains out of frame. However, scientists can see more of it today than ever before. And new pieces are coming into focus all the time, shedding light on the likely role that genetics play not only in MS risk but also in MS progression. Like a pianist knowing which keys to play to create the most melodious chords, understanding which genes contribute to disease susceptibility and severity could help scientists develop new and better therapies with which to treat MS and MS-related symptoms.

Genetics and MS Risk

To understand where genetic research in the MS community is going, it's helpful to understand more about where it has been, suggested Dr. Jokubaitis, who said the initial MS-related genetic variant that scientists discovered in the HLA region—known as (HLA) DRB1*1501—was just the beginning.

“Loads of people carry this variation within the HLA area of the genome, and loads of those people do not have MS despite carrying it. So that variation in and of itself was not enough,” explained Dr. Jokubaitis, who said research consortia like the International Multiple Sclerosis Genetics Consortium (IMSGC), the MultipleMS Consortium, and the Australian and New Zealand MS Genetics Consortium (ANZgene)—of which she is currently chair—have been actively searching for other genetic variations that might play a role in MS risk alongside (HLA) DRB1*1501.

“In about 2007, the IMSGC published a paper showing that there were a number of other regions within the human genome, above and beyond the HLA, that regulate MS risk. After that, ANZgene came in and added more variants. And several years later, they published even more,” Dr. Jokubaitis continued. “So we now know that there are more than 230 variations within the human genome that regulate an individual's risk of developing MS. The HLA region is still the main one, but each of these other 230-odd variations carries a tiny, incremental increase in risk.”

Scientists know that people with MS have more of these genetic variations than people who do not. What they do not yet understand is why, or what combination of genetic variations might create a sort of genetic “tipping point” for the disease. “It's all very complex, so people are still trying to get their heads around exactly how the genetics work,” Dr. Jokubaitis said.

Complicating things even further is epigenetics—the study of how genes express themselves differently in response to environmental or behavioral circumstances, without fundamental changes to one's DNA.

“The best way to think about the epigenome is, it's a little bit like syntax and punctuation,” Dr. Jokubaitis explained. “We only have 26 letters in the alphabet, and yet we can make that into any amount of prose you could ever conceive by chunking letters together in a particular order, which depends on us being able to capitalize letters and insert commas, full stops, quotation marks—whatever it happens to be. How we interpret the 26 letters of the alphabet depends on how we use punctuation and syntax. That's what epigenetics is to our DNA.”

Although some of the epigenome is inherited, other parts of it can change over time in response to diet, smoking, disease-modifying therapies, and chemical exposures, among many other things. When that happens, the genes themselves remain unchanged, but the body might flip the genetic equivalent of a light switch to turn some genes on and others off.

“So, whilst we might have these variations in our genetic code that will increase or decrease our risk for developing MS, our environment adds another layer on top that helps our bodies determine how to interpret our DNA in ways that might push us over the edge to either develop MS or not,” Dr. Jokubaitis said.



Genetics and MS Severity

Scientists who continue to look for genetic risk factors for MS also have stumbled upon genetic tripwires that might play a role in MS progression and severity.

Dr. Jokubaitis is among them. “What we know about multiple sclerosis is that people have vastly different outcomes. Some people have relatively mild MS compared to other people, and really great disease stability for a very long time. That’s not to diminish the symptoms they feel, but it might not be nearly as bad as it can be for some other people whose disease progresses very rapidly,” she said. “So, it made sense to me intuitively that there might be something in a person’s genetics that could help determine their disease outcomes.”

To investigate her hypothesis, Dr. Jokubaitis turned to MSBase, whose Scientific Leadership Group she currently chairs. An observational registry of clinician-reported MS outcomes, MSBase counts among its members researchers all over the world who are interested in the genetics of MS. Dr. Jokubaitis partnered with three of them to analyze the DNA of more than 1,800 individuals with MS who are in the MSBase registry.

“Like NARCOMS, the really cool thing about MSBase is that we have longitudinal outcomes data. The people participating in our registry have been followed for a very long time—one visit every six

months for up to 40 years in some cases. So, we can see really well how their MS has progressed over the years,” Dr. Jokubaitis explained.

Researchers divided their subjects into three groups: the 20% with the worst disease outcomes, whose MS progressed quickly; the 20% with the best disease outcomes, whose MS was stable and did not progress quickly; and the remaining 60% who fell somewhere in the middle. Next, they performed a genome-wide association study looking specifically at the mild and severe groups of individuals.

“The main criticism of our work is that we only had a sample size of 1,800 people, which for genetic association studies is very small. But the power that we had was this long-term data that was really, really well-defined,” noted Dr. Jokubaitis, whose team initially failed to find any statistically significant associations between genetic variants and disease severity, although they got “very, very close.”

Undeterred—they attributed their failure to their small sample size—they developed a machine learning algorithm that could parse their data further. “There are a lot of advantages to machine learning and artificial intelligence, because they can see patterns that we can’t see,” Dr. Jokubaitis said. “Machines can pull together information that we can’t possibly be able to compute ourselves, and that’s really exciting.”

Although they still fell short of the threshold for statistical significance, their findings—published in November 2022 in the journal *Brain*—were illuminating.

First and foremost, they discovered for the first time that the levers for MS severity are genes that regulate not the immune system, as is the case with MS risk, but rather genes that regulate the central nervous system. “That makes sense, because we know that MS is both an autoimmune disease and a neurodegenerative disease,” explained Dr. Jokubaitis, who said people with more severe MS were found to have variations in genes that affect how neurons connect to and communicate with one another. “We know that the brain is quite plastic and can therefore compensate quite well for damage. What this tells us is that those compensatory mechanisms aren’t as strong in people with more severe MS. Over time, because it’s being battered constantly by the immune system, the central nervous system isn’t able to rewire itself sufficiently enough to maintain the connections between neurons.”

Also evident in people with severe MS were genetic signals related to the production of myelin, which the immune system targets and damages in people with MS. “Myelin is the fatty sheath that allows signals to pass between neurons,” continued Dr. Jokubaitis, who said the finding—which again fell below the threshold for statistical significance—further supports the notion that there are genetic variations in the nervous system that are responsible for MS progression and severity.

In July 2023, the IMSGC and the Multiple MS Consortium published a study of their own in the journal *Nature*, echoing the findings of Dr. Jokubaitis and her colleagues, but with the benefit of a much larger sample size—22,000 people instead of 1,800. “They basically found what we found, but they found one signal that surpassed the . . . threshold [for statistical significance]. That means there’s now one

genetic variant that is associated statistically with MS severity, and that genetic variant is expressed by oligodendrocytes, the cells that make myelin,” Dr. Jokubaitis said.

Sergio Baranzini, PhD, a professor at the University of California, San Francisco and co-author of the IMSGC study, described the finding in stark terms. “Inheriting this genetic variant from both parents accelerates the time to needing a walking aid by almost four years,” he said in a news release.

Combined, Dr. Jokubaitis said her study and the IMSGC study send a powerful message to scientists who are working on MS treatments: MS risk and MS severity have different genetic underpinnings, with severity hinging on two possible drivers—a lack of compensatory mechanisms in the nervous system and dysfunction in the myelination process.

Unlocking Next-Gen Therapies

To the layperson, genetics and epigenetics are admittedly esoteric. You do not have to understand the human genome, however, to appreciate the significance of genetic research in the MS community.

On first blush, that research might seem discouraging. After all, you cannot control your genes. But Dr. Jokubaitis sees things differently. Instead of an immutable genetic destiny—a predisposition toward acquiring MS, for instance, and developing severe illness, quickly—what she sees in the data is opportunity for intervention.

“What the research shows to me is that your genes are not your fate,” said Dr. Jokubaitis, who noted that the genes responsible for MS severity so far have been found to have low heritability—less than 20%, to be precise. That means less than 20% of an individual’s disease outcomes are because of genes they inherited from their parents. For now, at least, the remaining 80% appear to be due to environmental factors, including the use of disease-modifying


therapies. “We know that disease-modifying therapies work in multiple sclerosis, and disease-modifying therapies would not work if your genes were your fate. The environment matters and can change the course of your MS.”

If that’s the case, her research and that of the IMSGC are a roadmap that could lead drugmakers to new levers they can pull to impact MS progression. “The really cool thing about the research we’ve done is that we now know there are weaknesses in the central nervous system and in the myelination process, which gives us new ideas as to where to look for new drug targets,” Dr. Jokubaitis said.

Because MS risk and severity hinge on many genes with incremental impacts instead of just one “silver bullet” gene, new treatments won’t involve genome editing, which shows promise for treating inherited diseases like cystic fibrosis, hemophilia, and Huntington’s disease, just to name a few. Instead, they’ll likely involve molecules that target various biological pathways, Dr. Jokubaitis theorized. “For example, it might be an antibody that targets a particular protein that needs to be switched on or off if there’s a weakness within synapses [in the central nervous system]. Or maybe there will be a therapy that will enable oligodendrocytes to switch from sort of a silent state into a pro-myelinating state,” she said. “New therapies will be about changing cell behavior as opposed to changing the DNA itself.”

It will not be easy, but the potential is plain to see. “Once we do find drugs that affect our epigenome—drugs that can switch genes on and off—our biggest challenge will be delivery of those drugs directly to the central nervous system,” Dr. Jokubaitis continued. “If we’re trying to get molecules into the nervous system, how do we get them in there in a way that bypasses all the mechanisms that exist in our body to prevent them from being in there? There’s a lot

of really cool research being done at the moment, looking at all sorts of nanoparticles that can be used as little delivery systems to bypass the body’s defenses and then open up to release drugs inside of cells.”

MS is not a genetic disease, per se. At least, not in the purest sense. By understanding its genetic and epigenetic components, however, scientists like Dr. Jokubaitis are forging new pathways by which to improve longevity and quality of life for people with MS. Like most things that come with indecipherable instructions—Barbie Dreamhouses and IKEA furniture, for example—there’s a lot of work involved to put it all together. At the end of the day, however, the reward promises to be as large as DNA is small. 





Introducing A New Feature In NARCOMS: An Individual Data Report

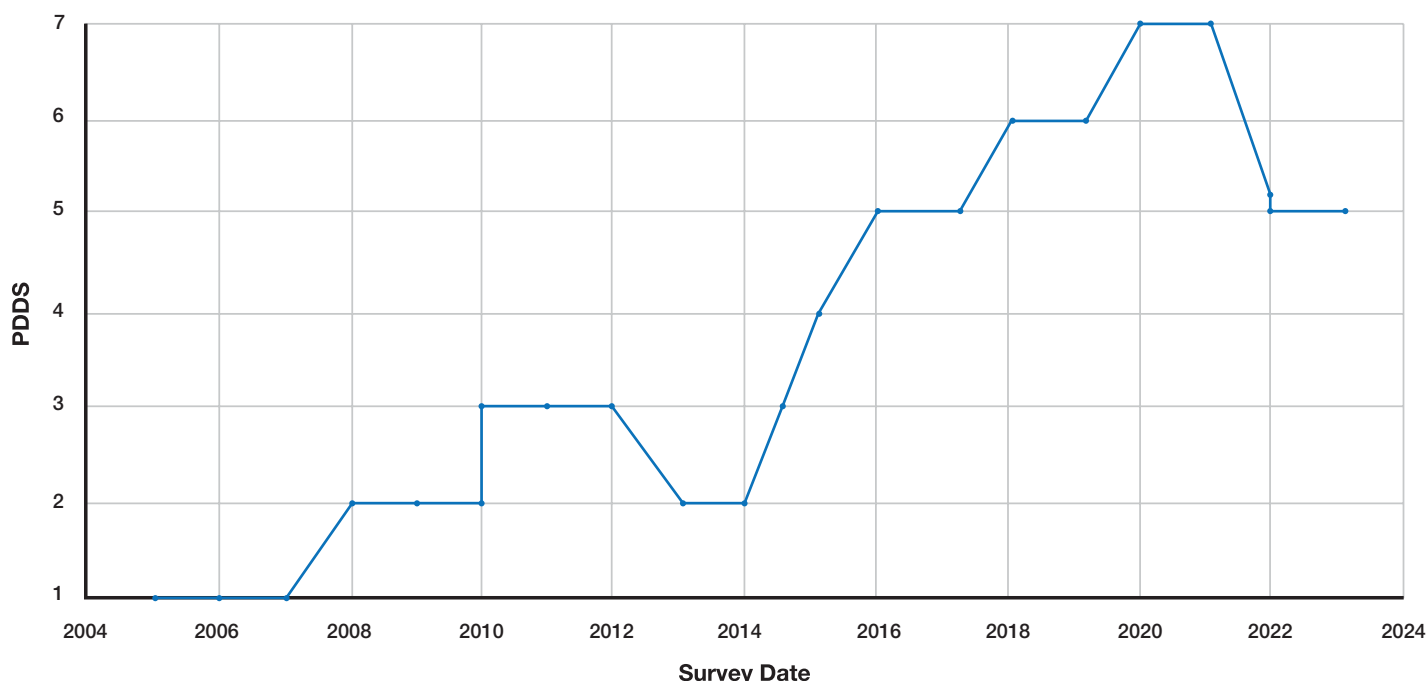
IN THIS EDITION OF SNAPSHOT, we describe something new for NARCOMS participants. Over the years, we have been asked to provide data to participants, but many of you have been in the registry for a long time! Providing your data over many years is challenging. We created a new report for participants—the *NARCOMS Individual Data Report*—which is an analysis of your individual responses from your time in the NARCOMS Registry. The report includes a visual of two long-standing components of the NARCOMS survey: the Patient Determined Disease Steps (PDDS), and the Health

Survey, which assesses physical and mental quality of life over time. In addition, we hope the Report helps the participant in understanding their own journey, and the personalized data may assist participants in discussions with healthcare providers and in making informed decisions about their care and lifestyle.

Descriptions Of The PDDS And Health Survey

The PDDS and the Health Survey have been part of the biannual surveys since the early 2000s.

Patient Determined Disease Steps (PDDS)



In the last issue of NARCOMS Now (Issue 12[3] 2023), we discussed the participants' PDDS data and how this related to employment (i.e., days missed due to disease complications). However, the PDDS offers other insights into participant disability and how disability affects quality of life. PDDS was developed as a self-assessment scale that allows individuals with MS to gauge their disability status. It is a vital tool for tracking disease progression. These data can be used to monitor disability progression, and how this relates to treatment, comorbidities, and quality of life in people with MS.

The Health Survey is a brief, widely used tool to measure the impact of health on an individual's quality of life. It gives physical and mental health summary scores, which offer insight into how MS affects participants' daily lives beyond the physical symptoms, encompassing overall well-being. The use of the Health Survey in NARCOMS surveys

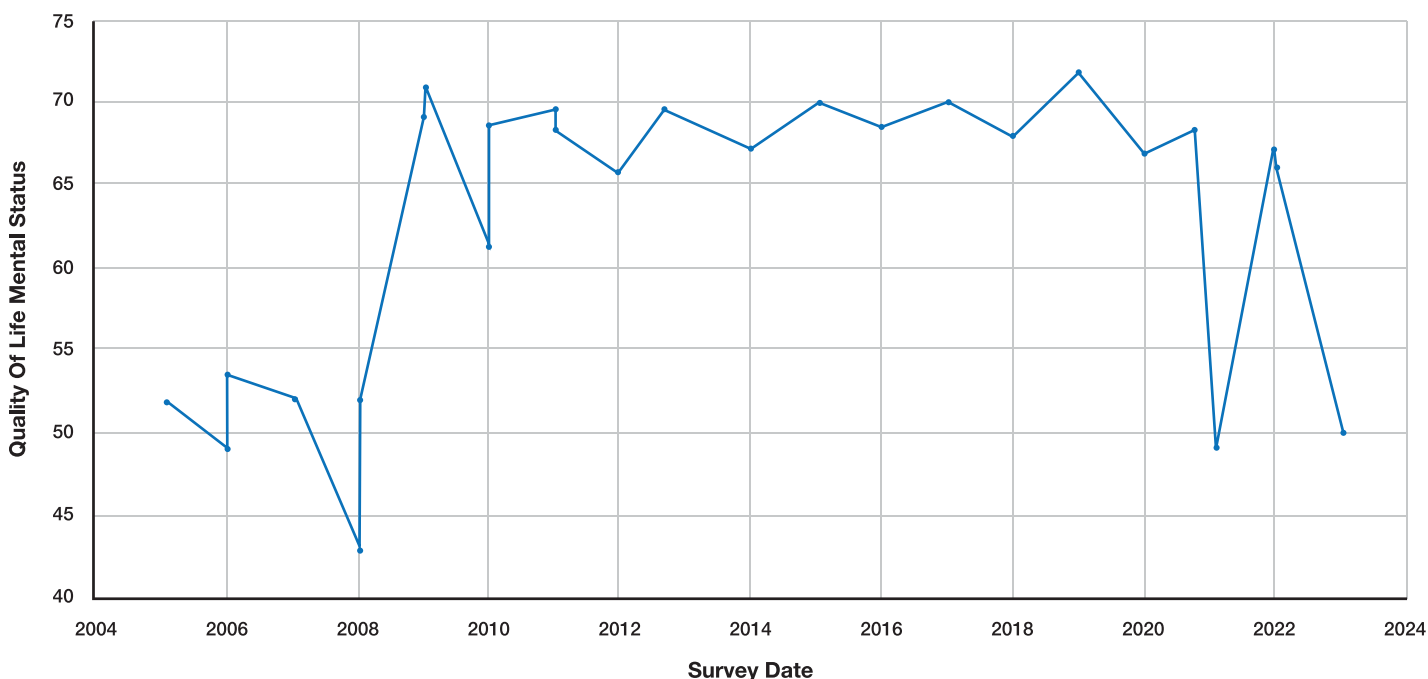
reflects a holistic approach to understanding the lived experience of MS, acknowledging that the disease affects more than just physical health.

The *NARCOMS Individual Data Report* summarizes these data graphically to provide a view of changes in these data over time. The granularity of these plots allows for a nuanced understanding of MS progression, highlighting periods of stability, improvement, or decline.

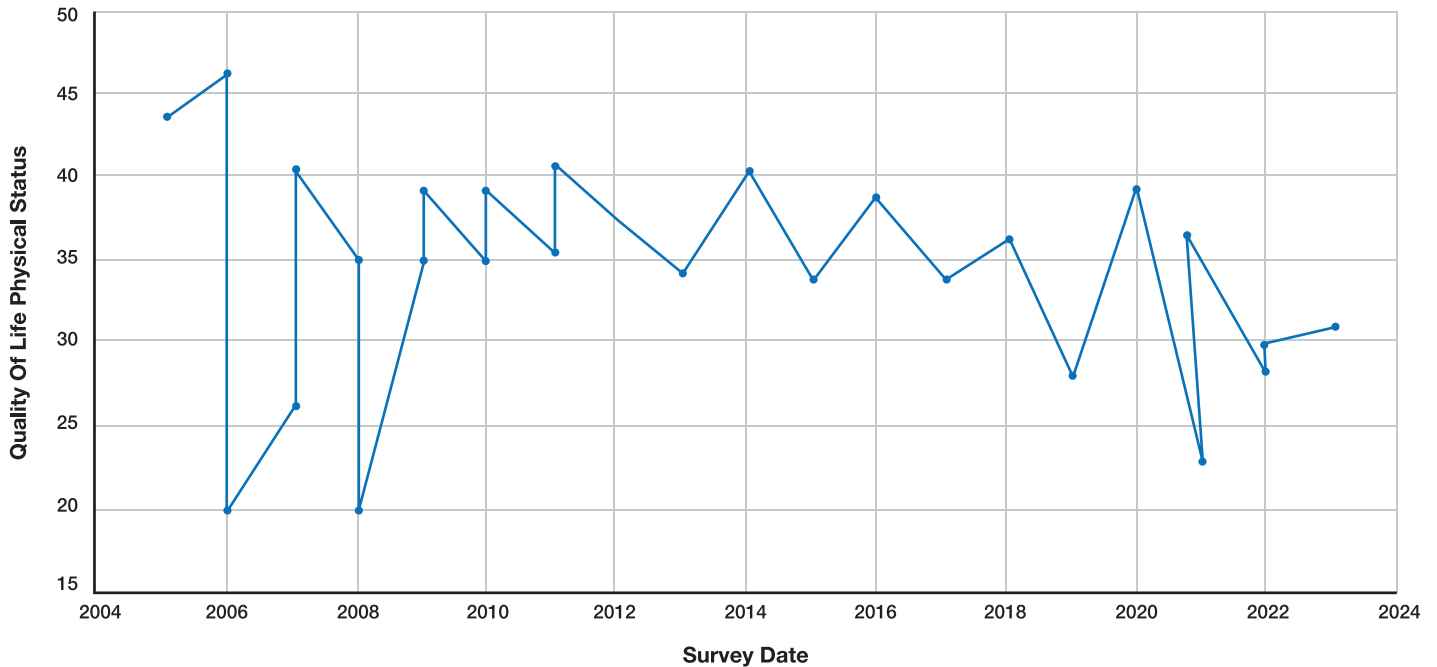
Graphical Representations In The NARCOMS Individual Data Report

The NARCOMS Individual Data Report uses line graphs to display participants' PDDS scores and the Health Survey physical and mental summary scores over time (Figure). These graphical representations in the report are key to helping participants discern trends in their disease progression and its impact on quality of life.

Mental Quality Of Life Summary Score



Physical Quality Of Life Summary Score




For interpretation of the Report, participants should note the trajectory of the lines. Upward trends in the Mental Health Quality of Life Summary Score and the Physical Quality of Life Summary Score indicate improvements in quality of life. In contrast, upward trends in the PDDS scores reflect increases in disability.

In large national surveys of the entire US population, the Mental Health Quality of Life Summary Score and the Physical Quality of Life Summary Score have an average score of 50 and a standard deviation of 10. Scores above 50 indicate a better health status than the typical person in the general US population, regardless of age. Scores below 50 indicate worse health status than the typical US person. For PDDS scores, a higher score indicates more severe disability, with highest scores indicating a severe or complete loss of mobility. The blue line is a continuous timeline, and two different data points in a single year indicates a change in scores between surveys.

Distribution To Active NARCOMS Members

The initiative to develop and offer the *NARCOMS Individual Data Report* to survey participants began as a pilot, and we thank those 400 participants who provided us with valuable feedback. The feedback from the pilot initiative was overwhelmingly positive, suggesting that most participants are keen on receiving such detailed reports about their health progression. Given its success, we are excited to extend this report to all active members of NARCOMS Registry beginning with the Spring 2024 Survey. NARCOMS recognizes the invaluable contribution of participants to MS research and offers the Reports to provide participants direct insights derived from their shared data.

We hope that you take some time to look over your personalized report, and please let us know what you think! 



Into The “Belly Of The Beast” – Do Gut Microbes Influence A Person’s Predisposition To Being Diagnosed With MS? New Research Says “Yes”

WITH A LIFE-ALTERING IMMUNE DISEASE like multiple sclerosis (MS), a lack of understanding of the cause of the disease is a great source of pain and confusion for those affected. It is accepted in the medical community that MS is caused partly by genetic factors. However, research interest is increasing in the role that bacteria in the gut, or the microbiome, may play in causing MS. A recent study* examined 117 MS patients and 26 healthy controls for two causes of multiple sclerosis—genetic risk factors and each patient’s microbial makeup—to determine whether people with MS have a distinct gut microbiome that has predisposed them to the disease.

By looking at blood samples and fecal samples of each participant, researchers were able to calculate genetic risk scores for MS and assess individual microbiota makeups to determine whether there was a link between gut microbiomes and MS diagnoses. Participants with relapsing-remitting MS (RRMS) were divided into two groups: treated and untreated. Treated and untreated RRMS patients showed a higher genetic risk of MS compared to control

participants. In addition, untreated RRMS patients showed a higher genetic risk of MS compared to treated RRMS patients.

All MS patients and controls were split into two clusters—A and B—based on the composition of their microbiome. All participants in group A, which included all controls, displayed a gut microbiome closely similar to the healthy control group. All participants in group B, which included no controls, had a gut microbiome composition that was different from that of group A.

These results suggest that there may be an association between an individual’s genetic risk for a diagnosis of MS and the composition of their gut microbiome. More studies are needed to understand the relationship between the genetic risk for MS and the gut microbiome.

REFERENCE

*Elsayed NS, Valenzuela RK, Kitchner T, et al. Genetic risk score in multiple sclerosis is associated with unique gut microbiome. Sci Rep. 2023 Sep 27;13(1):16269. doi: 10.1038/s41598-023-43217-4. PMID: 37758833; PMCID: PMC10533555.

Impact Of Genetic Variation On Vitamin D Levels, Disease Onset, And Disease Severity In People With MS

RESEARCHERS HAVE CONTINUED TO EXPLORE the link between Vitamin D and the development of MS. Recently, a study* reported that a specific allele of the CYP24A1 gene encodes an enzyme that can limit the amount of the active form of vitamin

D available in tissues and suggests a role of this CYP24A1 allele in MS. This study examined the impact of this “risk” allele on the severity of the disease and the patient’s age during diagnosis.

People with MS carrying the CYP24A1 risk allele and those without the risk allele participated in the study. Researchers examined two forms of Vitamin D in participants' blood, as well as pro-inflammatory and anti-inflammatory markers. Carriers of the risk allele had lower levels of one form of Vitamin D and higher levels of certain pro-inflammatory molecules in their blood compared to those without the risk allele.

People with MS carrying the CYP24A1 risk allele showed a younger disease onset compared to those without the risk allele, but there was no difference in

disease severity detected between the two groups. The findings of this study suggest that people with MS carrying the risk allele have reduced serum Vitamin D and are younger at disease onset compared to those without the risk allele. However, the severity of MS symptoms is similar between the two groups.

REFERENCE

*Malhotra, S., Midaglia, L., Chuquisana, O., et al. (2023). The CYP24A1 gene variant rs2762943 is associated with low serum 1,25-dihydroxyvitamin D levels in multiple sclerosis patients. *European Journal of Neurology*, 30(8), 2401–2410. <https://doi-org.ccmah.onionet.org/10.1111/ene.15866>


A 30-year Study Of Clinically Isolated Syndrome – An Indicator Of Future MS – To Assess Health Outcomes And Gene Variations

PEOPLE WITH MS CAN SHOW varied symptoms and symptom severity over many decades of disease progression. This makes it difficult to assess disease progression at any one time to determine disability and MS type. In a recent publication of a long-term study*, researchers analyzed 27 genes in 61 clinically isolated syndrome patients (young adults with episodes of symptoms that may lead to a diagnosis of MS) over a 30-Year period to determine if these genes may be related to disease progression and changes in brain MRI findings over time.

The genes were identified in a review of previous studies as possibly associated with the development or progression of MS. While the results suggest that long-term clinical outcomes of disease progression are dependent on multiple genetic influences (polygenic), specific genetic variations were associated with different long-term outcomes:

1. Participants with the specific gene variation HLA-DRB1*1501 tended to have more white matter lesions in their brains, more relapses, and a higher risk of developing secondary progressive MS.

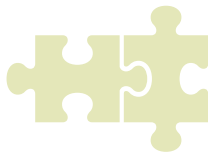
2. The gene variation PVRL2 was associated with more cortical lesions in the brain, worsening disability over time, and a higher risk of developing secondary progressive MS. Cortical lesions are damaged areas of the brain's cortex that can result in loss of muscle control, cognitive deterioration, and more.
3. Participants with the gene variation IRX1 seemed to have better outcomes overall. They had less grey matter loss in the brain, fewer cortical lesions, and slower disability progression.

The study results associate long-term MS outcomes with genetic influences, disease progression and pathological findings. Further study using larger patient populations and a broad genetic analysis may reveal critical associations between specific cellular processes and disease progression. 

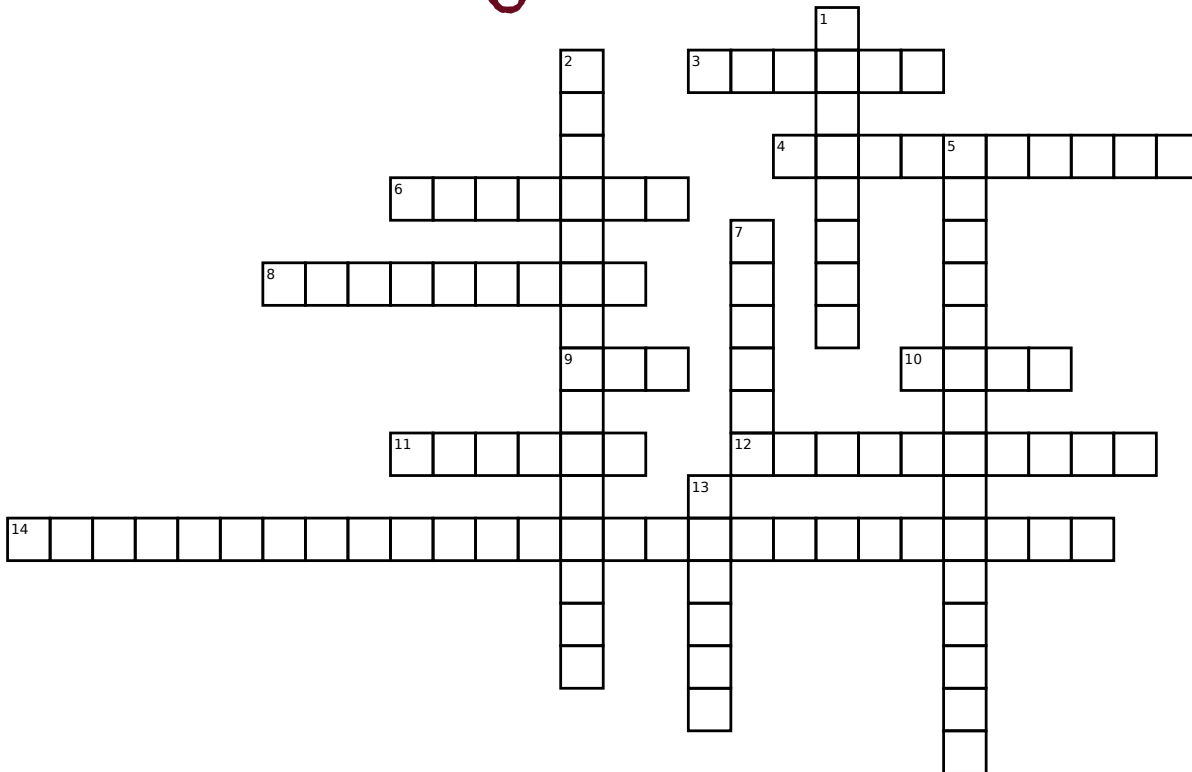
REFERENCE

*Sahi N, Haider L, Chung K, et al. Genetic influences on disease course and severity, 30 years after a clinically isolated syndrome. *Brain communications*. 2023;5(5):fcad255. doi:10.1093/braincomms/fcad255

CROSSWORD



Play CROSSWORD



DOWN

1. Collections of data related to patients with a specific condition that play an important role in clinical research
2. The study of the interaction between the nervous and immune systems
5. A type of cell in the nervous system that produces myelin
7. The centermost point of something
13. The complete set of genes of an individual

ACROSS

3. Different version of a gene
4. All bacteria in the gut
6. ____ nervous system, consists of the brain and spinal cord.
8. Multiple genetic influences
9. An imaging technique used to monitor disease progression in MS
10. Abbreviation for a self-assessment scale of disability status
11. A type of large building where people go to gamble
12. Environmental or behavioral influence on gene expression
14. Episodes of symptoms that may lead to a diagnosis of MS



MSMESSENGER



The Spring 2024 Survey will be available beginning in April. Please be sure to return your paper surveys or complete the online survey if you have not yet done so. Thank you for your participation!



As a refresher for those who complete their surveys online: you no longer need to go to the NARCOMS website to access your surveys, and you do not need a username or password. A link to your individual survey is emailed to you. You can just click on that link to access your survey. If you need to take a break, you can use the “save and return” function. A return code will be shown on the screen that you should save so you can access your partially completed survey when you are ready to complete it. You can also enter your email address to have the return code emailed to you.



As always, you can update your contact information by telephone at (214) 648-4583 or by email at msregistry@narcoms.org.

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NARCOMS NOW

BE PART OF NARCOMS—HELP TO ADVANCE RESEARCH IN MS



Whether you were recently diagnosed with multiple sclerosis (MS) or have lived with it for years, your personal history with the disease helps contribute to improving the lives of others with MS.



Participation in the NARCOMS registry allows you to be part of the process. The data provided by participants gives researchers a clearer picture of how a condition like MS impacts the lives of those affected.



Participation in NARCOMS is confidential—your information is kept secure and completely private. If you have MS and are not yet participating in NARCOMS, or have been out of touch for a while, we would love to hear from you!

Contact us via email at MSRegistry@narcoms.org.



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