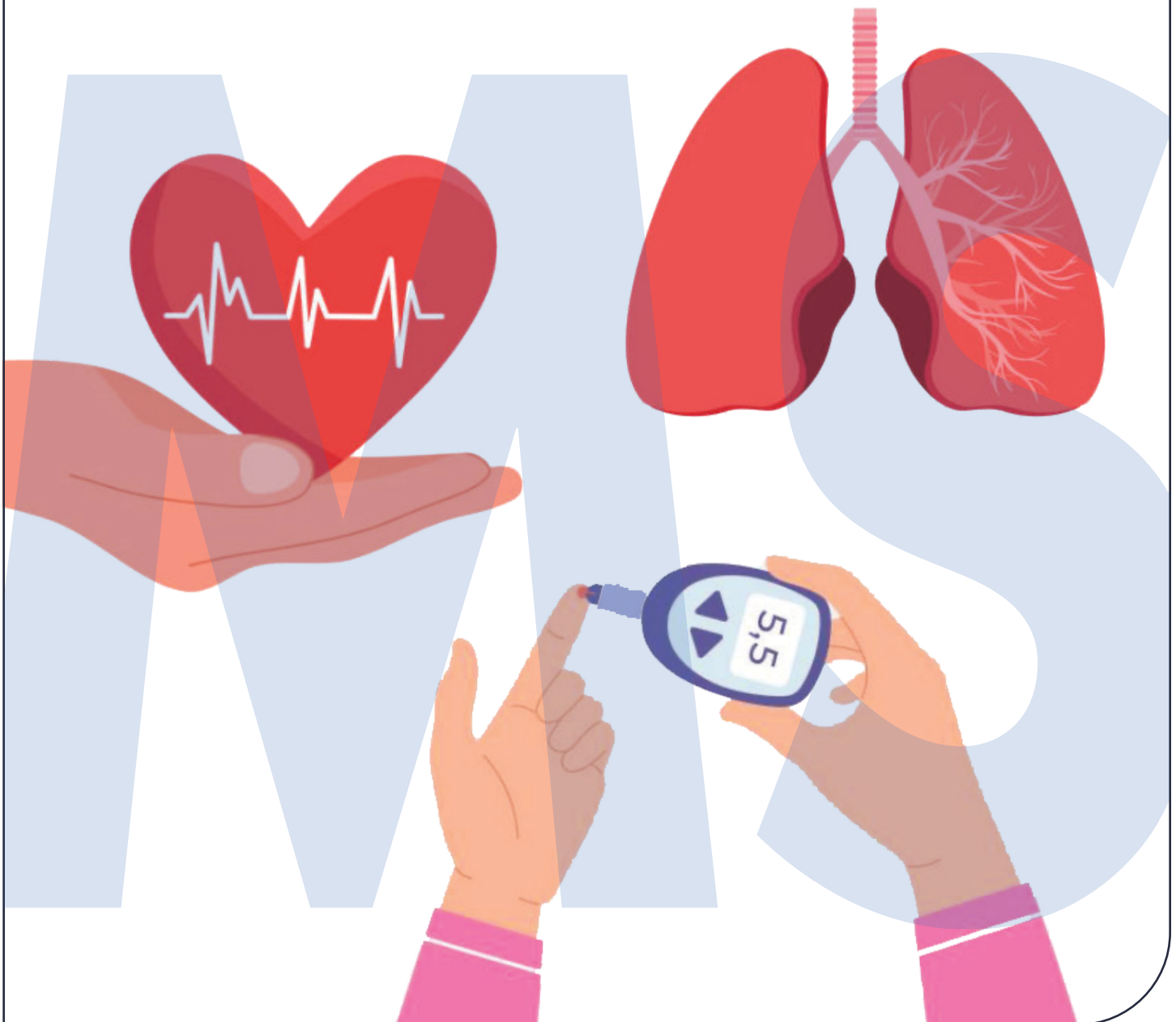


## Comorbid Conditions: What Do They Mean for People with MS?



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## INFOCORNER



### 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 are 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](http://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](mailto:MSRegistry@narcoms.org)

**Online:** [www.narcoms.org/contact-us](http://www.narcoms.org/contact-us)

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# DIRECTOR'S LETTER

Dear NARCOMS Now Readers:

In this issue of NARCOMS Now, the Feature Focus examines evidence of co-existing health conditions, or “comorbidities,” that occur in people with MS and other neurologic diseases. Comorbidity affects people with MS throughout the disease course and we need to understand more about how to treat these comorbidities and how they affect the course of MS. This is accompanied by an interview with Dr. Kaarina Kowalec about the role of genetic factors in the relationship of depression and MS.



Ruth Ann Marrie, MD, PhD

In the SnapShot, we examine the use of NARCOMS Registry data in MS research from 2004 to the present, and the breadth of topics covered in recent studies. We present summaries of a few studies that show the power of your participation in the registry.

In the MS News sections, we review a recent report about the role of genetics in the predicting the risk of liver injury with the use of interferon-beta therapy. In addition, we examine the results of a clinical trial that looked at the potential benefits of vitamin D and fish oil supplements on risk of several diseases. Finally, we summarize a study examining the use of a “standing frame” and its impact on motor function and falls.

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

Sincerely,

Ruth Ann Marrie, MD, PhD  
Scientific Director, NARCOMS



# FEATURE FOCUS

## Comorbid Health Conditions: What Do They Mean for People with MS?

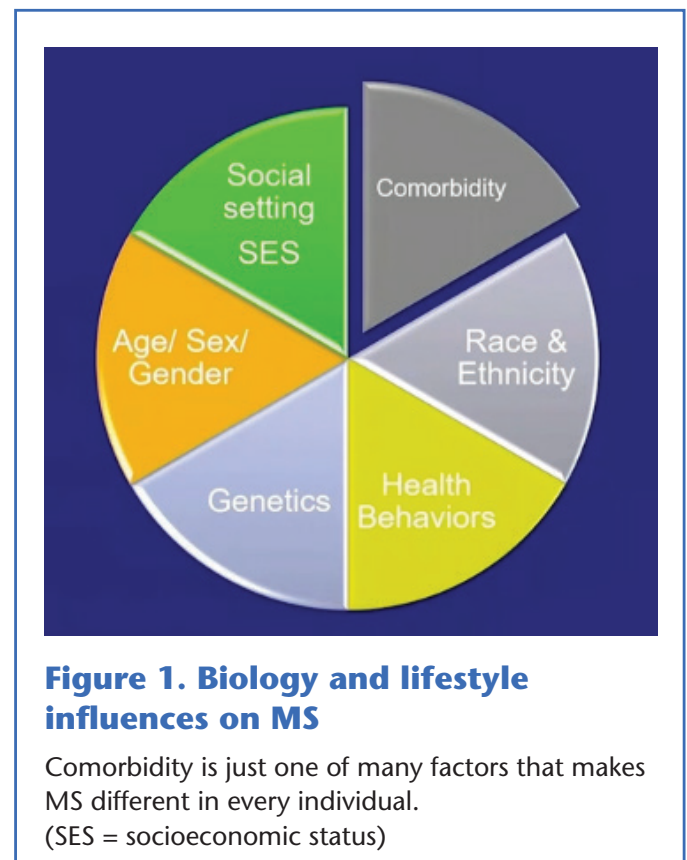
**H**ayley, a 47-year-old mother of two, experienced blurred vision and some numbness and tingling in her feet. Up to this point, her multiple sclerosis (MS) had seemed mild and usually well-controlled. With these new problems, she was concerned that her MS might be getting worse. “It was a long road,” Hayley said, “before we figured out that these symptoms were actually due to [a new diagnosis of] diabetes.”

Modern medicine, especially in Western cultures, tends to view the body as isolated parts, rather than seeing the person as a whole. For example, treatment of heart disease might focus on the heart without considering other body systems. Many people with MS have noticed that their MS condition tends to overshadow other aspects of their health.

NARCOMS Scientific Director Ruth Ann Marrie, MD, PhD, specializes in the study of co-existing health conditions, or “comorbidities,” that occur in people with MS and other neurologic diseases. Earlier this year, Dr. Marrie was invited to give a lecture on MS and comorbid conditions at a scientific meeting called ACTRIMS. The lecture was given in memory of a noted neurologist, Dr. Kenneth P. Johnson.

“MS varies a great deal among individuals,” Dr. Marrie said in her lecture. “Viewing the disease

in isolation fails to take into account individual differences due to age, sex, medical history, and genetic makeup. This tends to discard an enormous amount of biological information about the individual and their life experiences prior to the development of the disease,” she said. These factors, (including behaviors like smoking or exercise habits) can make a difference in the risk of MS, the severity of symptoms, and how the condition progresses (Figure 1).



### Comorbid Conditions and MS

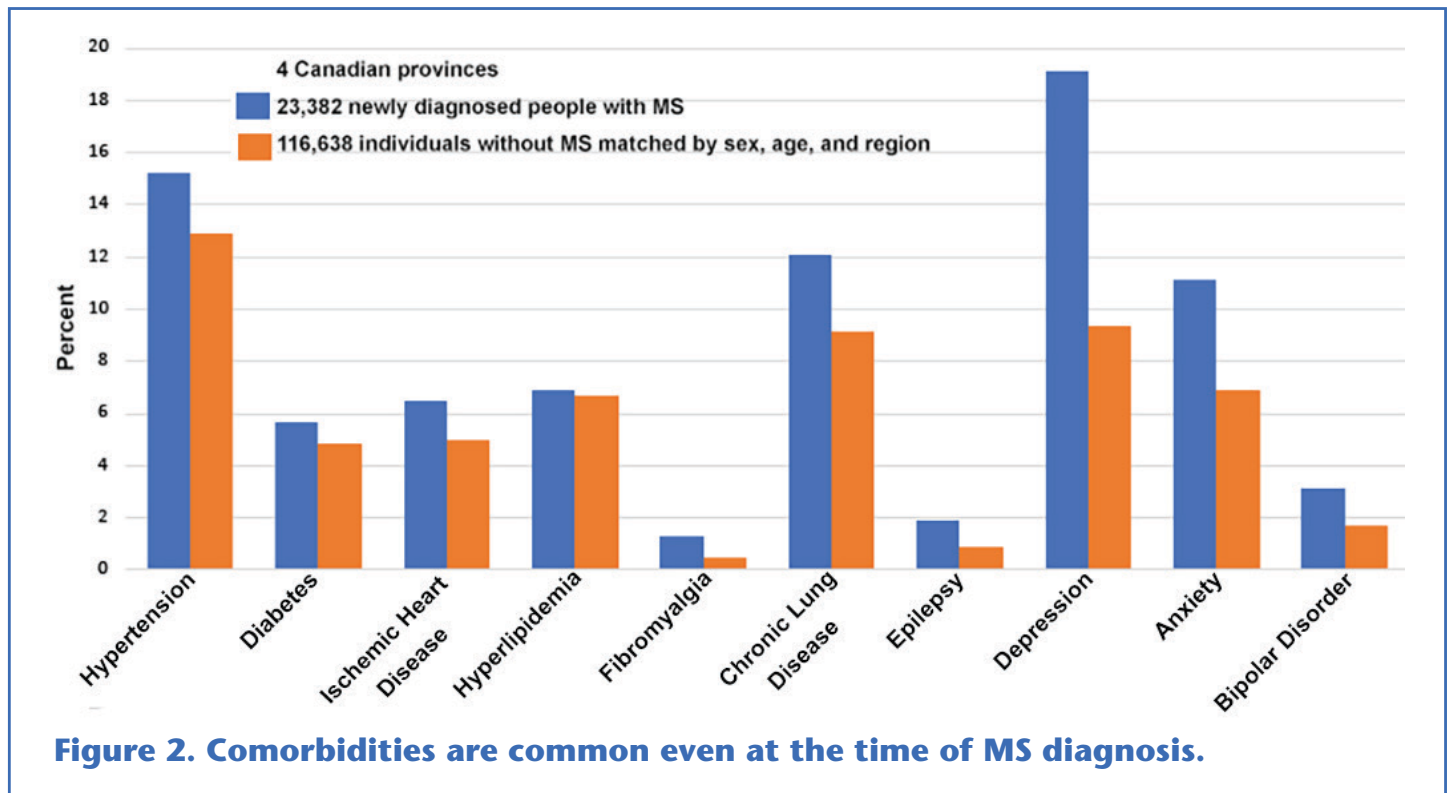
The term “comorbid” refers to a co-existing condition in someone who has another health condition, in this case MS. Some of the research using NARCOMS survey data is focused on learning more about MS and comorbidities.

Comorbid conditions can be seen very early in the course of MS, Dr. Marrie explained. One of her studies was based on health insurance (claims) data in Canada. One study identified over 20,000 individuals with newly diagnosed MS and looked for evidence of coexisting conditions. The most common comorbid conditions in people with MS in this study were depression, high blood pressure, anxiety disorders, high cholesterol, heart disease, and diabetes (Figure 2). This study also showed that these conditions were more common in people with MS at the time they were diagnosed with MS than in people of the same

age and sex who lived in the same region, Dr. Marrie said. Some comorbid conditions were present as long as five years before the first evidence of MS. This suggests that conditions like depression did not necessarily arise due to MS, since the conditions were present early on.

### Depression and MS

Depression and anxiety disorders remain relatively persistent in frequency among people with MS across age groups. In another study, Dr. Marrie’s research group looked at depression, anxiety, and other psychiatric conditions in people who had MS or another immune-mediated inflammatory disease (such as rheumatoid arthritis). “We found a clear spike in incidence (new cases) of these psychiatric conditions around the time of the MS/immune disease diagnosis,” Dr. Marrie said. “This is not unexpected, considering that the person is dealing with adjustment to an illness. But we found an increased incidence



of psychiatric disorders as early as five years before the first diagnosis of the inflammatory disease.” The incidence remained elevated after MS diagnosis, although slightly lower than in the first year after diagnosis. This pattern was consistent across all of the immune-mediated inflammatory diseases. This suggests that depression is not necessarily just a response to having a chronic illness. Some experts believe there may be a shared underlying biological link between MS and these psychiatric conditions. One of Dr. Marrie’s colleagues, Kaarina Kowalec, is studying gene patterns in people with MS to further explore this theory (see Sidebar).

**Other Comorbidities**

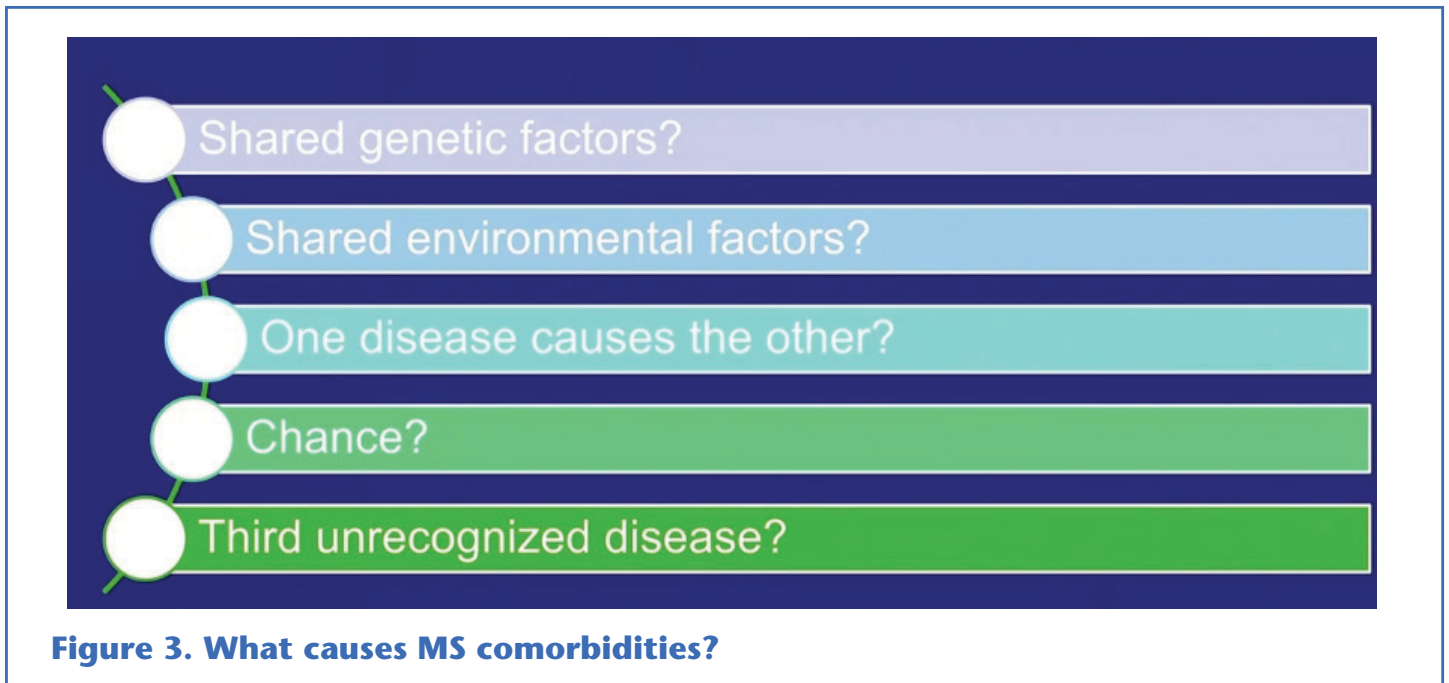
Studies by Dr. Marrie and others show that conditions like high blood pressure, heart disease, diabetes, and chronic lung disease occur more often in people with MS than in those without MS. “These conditions increase in frequency as a person ages, at a time when they are typically accumulating more disability

and their MS is becoming more complex to manage,” she said.

A person with MS may not be able to manage as many screening and “well” visits to check for other health problems, due to the burden of managing MS. For similar reasons, many also have difficulty finding the time and energy or motivation to exercise or eat properly. Hayley, introduced earlier in this article, said she knew she needed to do more to manage her overall health, but it always fell to the wayside due to competing demands like her children’s healthcare and managing her MS medications. She was surprised when she had to “add diabetes to the list,” she said. “It was a real wake-up call that I needed to focus more on whole-person health.”

**Why does Comorbidity Occur More Often in People With MS?**

There are several potential explanations for why some medical conditions occur more often in people with MS (Figure 3). The reasons probably differ according to the



condition and the individual, Dr. Marrie said. “Broadly, when we ask this question, we’re thinking about possible genetic or environmental factors in common between MS and the co-morbidities of interest. Something about one disease may lead to the development (or increase the chances) of another. Random chance may be at play in some cases. Finally, there could be a third, unrecognized condition that at the root of MS and the comorbid condition.

### **Effect of Comorbidities on MS**

What is the effect of having comorbid conditions on MS itself? As discussed earlier, MS can delay the diagnosis of a comorbid health condition. Comorbid conditions can also delay the diagnosis of MS. A study based on NARCOMS survey data from 9,000 people with MS showed that having at least one additional health condition was associated with longer delays in the diagnosis of MS. Many factors could contribute to this delay, Dr. Marrie said. “The patient has to recognize that their symptoms are important and that they are not related to the existing condition. They have to present to a healthcare provider, who then must recognize that the symptoms require further investigation. This must progress to an appropriate referral and diagnostic testing.” At each stage, attributing the symptoms to an existing condition may cause delays along this pathway. Competing demands, where another health condition is simply a demanding all of the attention of the person or their health care team, can also create delays.

In the same study using the NARCOMS registry, Dr. Marrie and colleagues found that people with more comorbidities were more

likely to have severe disability with their MS, as assessed by patient-determined disease status.

NARCOMS survey data have shown that people with certain comorbid conditions need an assistive device to walk at an earlier stage than people without comorbidities. People with MS who did not have a vascular condition (like heart disease) went a median of 18 years before needing an assistive device to walk. Those who had at least one vascular comorbidity had just 12 years before needing an assistive device. This 6-year gap persisted even after the researchers accounted for disability level at diagnosis, socioeconomic status, race and ethnicity, disease-modifying therapies used, and other factors.

Another study showed that the risk of heart disease affected the risk of MS relapse. The Framingham score predicts the risk of heart disease. This score considers factors such as age, weight, smoking history, blood pressure, and diabetes. In the study, the authors found that a 1-point increase in the Framingham score was associated with a 30% increase in MS relapse rate, a 19% increased risk of needing a cane to walk, and a 62% increase in the risk of needing a higher-efficacy disease modifying therapy.

“Comorbidity affects MS throughout the disease course,” Dr. Marrie concluded. “It is associated with diagnostic delays, increased relapse rates, accelerated disability progression, and other complications associated with managing MS. We need to understand more about how we’re treating these comorbidities, how treating them affects the course of MS, and how to best manage the health of the individual as a whole.”

## Why Are Depression and MS Inter-related?

**NARCOMS Now talks with Canadian Researcher Kaarina Kowalec, MSc, PhD**



*Kaarina Kowalec, PhD, is Assistant Professor in the College of Pharmacy at the University of Manitoba in Canada. Her research focuses on applying the latest knowledge of genes and “precision medicine” in an effort to better understand neurologic diseases like multiple sclerosis (MS).*

### **What does “precision medicine” mean in MS, and how can research like yours contribute to that idea?**

Precision medicine means selecting the best treatment for an individual based on several factors, including genetic makeup. One of our studies is investigating why some people with MS have poorer response to MS treatments. Right now, we do not know why some people with MS have a poor response to some therapies. By better understanding these issues, we may be able to select more effective therapies for a given person. This could also help to avoid adverse reactions from drugs that are not the best fit for that person. Our research is looking for possible genetic links or connections that might explain these poor outcomes in people with MS and other immune-mediated diseases. This includes gene variations that might provide some clues to poor outcomes. We are also looking for genetic connections between MS and certain co-existing medical conditions, like depression.

### **Let’s talk about those comorbid conditions. Why do people with MS have more depression? Is it mainly a reaction to having a chronic disease?**

It might seem natural that people who are diagnosed with MS would experience some degree of depression. We do see a rise in the diagnosis of depression around the time of an MS diagnosis. But research shows that

depression is present more often in people with MS even many years before their MS diagnosis. The degree of depression levels off for some people after they adjust to having MS, but overall rates of depression remain higher than the general population.

### **Are there any common genetic traits that may explain higher rates of depression in people with MS?**

Our research is looking at both genetic and environmental aspects. A person’s environment changes over the course of one’s lifetime, but your genetic sequence is the same whether you are 30 years old or 60 years old. In looking at DNA markers for depression, our research has shown that people with an immune disease like MS or inflammatory bowel disease show a “trajectory” of depressive symptoms over time. Those who experience chronically high depression often need greater support for this issue. If they are aware of the tendency for depression and MS to occur together, clinicians may be able to detect depression earlier and guide treatment decisions for that individual.

### **What are some other research studies that shed light on this issue?**

Research from the University of British Columbia by Helen Tremlett and colleagues showed that depression is one of the signs of a “prodrome” period that occurs with MS. This means that some signs or symptoms appear before the “classic” signs of MS like numbness or visual changes, often several years before. In the past, it was believed that MS did not have a prodrome stage. Now it is recognized that pain, sleep problems, migraine headaches, and depression/anxiety may be part of the prodrome period we associate with the period before onset of more typical early MS symptoms.





# SNAPSHOT

WHAT WE CAN LEARN FROM NARCOMS SURVEYS

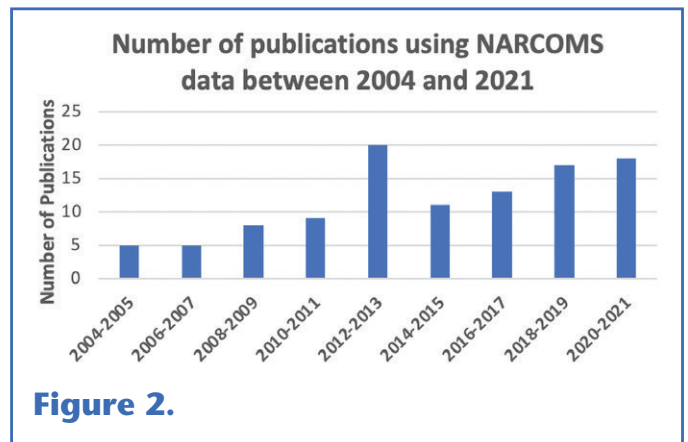
## How your contribution has helped MS research

As most NARCOMS participants are aware, the information you share with us is critical to advance our understanding of MS. The information you have shared about your experiences with MS has been used to clarify the impact of MS on individuals and families, to assess how well therapies work, to understand the various and shifting challenges for people with MS across the life-span, and to understand and classify the different types of MS. One way to measure the impact of your participation in the NARCOMS Registry is to look at the number of research studies that have relied upon NARCOMS data.

We searched a database that captures medical publications. Over 110 studies that used NARCOMS data were published in peer-reviewed journals between 2004 and 2021. These studies were conducted by researchers at public and private institutions and health care facilities across North America, Europe, and the Middle East (**Figure 1**). In addition, NARCOMS data have been used by future MS researchers in Master's and Doctoral degree work.

The rate of publication of studies using NARCOMS data has increased relatively consistently between 2004 and 2021, with 2012- 2013 being a particularly productive period (**Figure 2**).

To provide some perspective about the



research being enabled by your participation in NARCOMS, the following is a selection of studies published between 2020 and 2022:

- A propensity-matched comparison of long-term disability worsening in patients with multiple sclerosis treated with dimethyl fumarate or fingolimod. Salter A, et al. Therapeutic advances in neurological disorders. 2021;14. PubMed PMID: 34262613.
- A Survey of Cannabis Use in a Large US-Based Cohort of People with Multiple Sclerosis. International journal of MS care. Salter A, et al. 2021;23(6):245-52. PubMed PMID: 35035295.
- Abuse and neglect of people with multiple sclerosis: A

- survey with the North American Research Committee on Multiple Sclerosis (NARCOMS). Morrison EH, et al. *Multiple sclerosis and related disorders*. 2020;46:102530. PubMed PMID: 33032058.
- Attitudes toward coronavirus disease 2019 vaccination in people with multiple sclerosis. Marrie RA, et al. *Multiple sclerosis journal*. 2022;8(2). PubMed PMID: 35634013.
  - Cannabis Use for Symptom Management Among People with Multiple Sclerosis: A 2020 NARCOMS Survey. Wagner J, et al. *Archives of Physical Medicine & Rehabilitation*. 2021;102(10):e23-e4. PubMed PMID: 152647179.
  - Challenges and Opportunities in Progressive Multiple Sclerosis Trials: Lessons from Lipoic Acid...Waslo CS, et al. *International Journal of MS Care*. 2020;22(S2):10-1. PubMed PMID: 144209750.
  - Characterizing Long-term Disability Progression and Employment in NARCOMS Registry Participants with Multiple Sclerosis Taking Dimethyl Fumarate. Salter A, et al. *International journal of MS care*. 2021;23(6):239-44. PubMed PMID: 35035294.
  - Comparative responsiveness of the health utilities index and the RAND-12 for multiple sclerosis. Marrie RA, et al. *Multiple sclerosis*. 2021;27(11):1781-9. PubMed PMID: 33399503.
  - Comparing the MSIS-29 and the Health Utilities Index Mark III in Multiple Sclerosis. Marrie RA, et al. *Frontiers in neurology*. 2021;12:747853. PubMed PMID: 34975716.
  - Developing a crosswalk between the RAND-12 and the health utilities index for multiple sclerosis. Marrie RA, et al. *Multiple sclerosis*. 2020;26(9):1102-10. PubMed PMID: 31161917.
  - Disease-modifying therapy prescription patterns in people with multiple sclerosis by age. Zhang Y, et al. *Therapeutic advances in neurological disorders*. 2021;14. PubMed PMID: 33868459.
  - Disparities in Telehealth Care in Multiple Sclerosis. Marrie RA, et al. *Neurology: Clinical Practice*. 2022. doi: 10.1212/cpj.0000000000001167.
  - Gender identity and sexual orientation affect health care satisfaction, but not utilization, in persons with Multiple Sclerosis. Khayambashi S, et al. *Multiple sclerosis and related disorders*. 2020;37:101440. PubMed PMID: 32173004.
  - Maintenance of Working Status and Work Productivity in Persons with Multiple Sclerosis Treated with Dimethyl Fumarate: A 5-Year Analysis of the North American Research Committee on Multiple Sclerosis (NARCOMS) Registry. Salter A, et al. *International Journal of MS Care*. 2020;22(S2):15-6. PubMed PMID: 144209766.
  - Measures of general and abdominal obesity and disability severity in a large population of people with multiple sclerosis. Fitzgerald KC, et al. *Multiple Sclerosis*. 2019 PubMed PMID: 31079537.
  - Multiple Sclerosis Management and Expanded Disability Status Scale: A Great Start, but a Reason for Change Was Never So Apparent and Needed...Gudesblatt M, et al. *International Journal of MS Care*. 2020;22(S2):67-. PubMed PMID: 144209907.
  - New applications for independent activities of daily living in measuring disability in multiple sclerosis. Salter A, et al. *Multiple sclerosis* 2021;27(1):97-106. PubMed PMID: 31933419.
  - Pain-related illness intrusiveness is associated with lower activity engagement among persons with multiple sclerosis. Gromisch ES, et al. *Multiple sclerosis and related disorders*. 2020;38:101882. PubMed PMID: 31812040.
  - Perspectives From Persons With Multiple Sclerosis for a Comprehensive Real-World Change Therapy for Mobility. Archives of rehabilitation research and clinical translation. Mark VW, et al. 2021;4(1):100166. PubMed PMID: 35282147.
  - Physical and Mental Health-Related Quality of Life Trajectories Among People With Multiple Sclerosis. O'Mahony J, et al. *Neurology*. 2022. PubMed PMID: 35948450.
  - Rates and patterns of physical activity among Hispanics with multiple sclerosis in the NARCOMS Registry. *Multiple sclerosis and related disorders*. Silveira SL, et al. 2022;65:104018. PubMed PMID: 35810721.
  - Sources of Cannabis Information and Medical Guidance for Neurologic Use: NARCOMS Survey of People Living With Multiple Sclerosis. Salter A, et al. *Neurology Clinical practice*. 2022;12(2):102-12. PubMed PMID: 35733947.
  - The influence of trait mindfulness on depression in multiple sclerosis: potential implications for treatment. Miller JR, et al. *Quality of life research*. 2020;29(12):3243-50. PubMed PMID: 32613306.
  - Using the multiple sclerosis resiliency scale to identify psychological distress in persons with multiple sclerosis. Gromisch ES, et al. *Multiple sclerosis and related disorders*. 2021;53:103079. PubMed PMID: 34157629.

As the NARCOMS database continues to grow, so does the variety of questions about MS that can be addressed. Here, we present short summaries of a few studies that show the power of the NARCOMS registry and your participation in the registry.

In a recent article (Silveira, et. al., 2022), Drs. Stephanie Silveira and colleagues examined the patterns of physical activity among people who participated in the Spring 2015 NARCOMS Survey. They compared patterns of physical activity between participants who identified as Hispanic and those who



identified as non-Hispanic White. They found that there was little difference between the two groups in regards to physical activity. Notably, the levels of physical activity in both groups were somewhat low. This study was the first to look at physical activity behavior among Hispanic individuals with MS and points to opportunities across ethnic groups to encourage physical activity.

An article by Dr. Julia O’Mahony and colleagues reports a longitudinal analysis of health-related quality of life (HRQoL) in people with MS (O’Mahony, et. al., 2022). Rather than looking at data from a single survey or timepoint, it looked at the trajectory of change in health-related quality of life (HRQoL) over time. It used NARCOMS data from surveys conducted between 2004 and 2020. This study found that older age, worse physical impairments, and worse fatigue at diagnosis were associated with having the worst outcomes in HRQoL over time. These risk factors are easily identifiable by clinicians, which provides an opportunity for early intervention in the most at-risk patients.

NARCOMS Survey data have been used by students in becoming MS researchers. For

example, Marcia Jones, PhD, used NARCOMS data in her doctoral dissertation to investigate coping strategies used by people with MS to maintain optimal health. She identified the ability to maintain employment as a predictor of Perceived Health Status (health concepts relevant to the patient from the patient’s perspective). In particular, people with MS, who are unable to work, have worse physical and mental health than those who stay employed. Overall, MS can disrupt social, family, and work function leading to diminished Perceived Health Status, which is an important measure of patients’ conditions and treatment outcomes and can help with collaborative care.

In another example of NARCOMS data used in the education of future MS researchers, Marisa McGinley, MD, MS used NARCOMS data to better understand factors that are associated with patient decisions to stop disease-modifying therapies. The results suggest that a patient’s confidence in their ability to make good decisions about their own health care is an important factor in their ability to decide whether to continue or discontinue treatment. In addition, she found that continuous provider recommendations and education can enhance the patient’s decisional process. This research was the focus of Dr. McGinley’s Master’s dissertation.

As these few examples illustrate, there is no doubt of the value of the NARCOMS data in current and future MS research and the training of future MS researchers. Your participation in NARCOMS surveys is very important and much appreciated!



## Gene Study Identifies Patients with MS at Higher Risk for Liver Injury from Interferon Use

Interferon-beta is a therapy used by many people with multiple sclerosis (MS). Use of interferon-beta increases the risk of liver injury in some people. So, people who take interferon beta-1a or interferon beta-1b must have regular blood testing to identify possible liver injury. Standard blood tests measure liver enzymes. Elevated liver enzyme levels indicate that more liver cells are breaking down.

Researchers at the University of British Columbia in Canada found a genetic marker associated with a higher risk for interferon-beta-induced liver injury. Conversely, people without this gene variation (located on chromosome 1q32.2) appeared to be at very low risk for liver injury. Lead author Dr. Kaarina Kowalec noted that this was the first study to identify a genetic link to an adverse reaction from an MS therapy, specifically liver injury. The results suggest that a genetic test (from a blood or saliva sample) could identify people with MS who have a gene variation that puts them at higher risk for liver injury from interferons. This could help with a decision to select a different therapy or for the person to receive more frequent monitoring for liver injury.

The researchers noted that findings from this study only apply to people with European

genetic ancestry, based on how the study was done. “These findings have important implications for the development of strategies to reduce the occurrence of IFN- $\beta$ -induced liver injury in MS patients.”

### Reference

Kowalec K, Wright GEB, Drögemöller BI, et al. Common variation near *IRF6* is associated with IFN- $\beta$ -induced liver injury in multiple sclerosis. *Nat Genet.* 2018 August;50(8):1081–1085.

## Vitamin D and Fish Oil Supplements: Do They Help Ward Off Heart Disease or Cancer in Older Adults?

The relationship between vitamin D and multiple sclerosis (MS) risk has been studied widely. Many experts recommend use of vitamin D supplements. A study called VITAL (VITamin D and Omega-3 Trial) based at Harvard’s Brigham and Women’s Hospital has been exploring the relationship between vitamin D and other serious health conditions for over a decade. These conditions include cancer or cardiovascular disease/stroke. The study also looked at possible links between fish oil supplements (omega-3 fatty acids) and risk of these conditions.



The VITAL study included nearly 26,000 participants. Participants included men aged 50 and over and women aged 55 years and over who had no prior history of cancer, cardiovascular disease, or stroke at the time of study enrollment. Participants were provided with a regimen of supplements that included vitamin D and omega 3 supplements or placebo to take daily and filled out a questionnaire once a year. The follow-up period was approximately five years for most participants.

As reported by lead investigator JoAnn Manson, MD, DrPH, taking vitamin D supplements at a dose of 2,000 IU did not appear to be associated with lowered risk of either invasive cancers or cardiovascular events, compared with those who took no vitamin D supplement. Similarly, taking a 1 gram per day omega 3 supplement (also known as marine n-3) was not shown to lower the risk of either cardiovascular disease or cancer.

“Given the popularity of fish oil as a strategy to reduce chronic disease, clarifying the relation[ship] between supplemental n-3 fatty acids and risks of cardiovascular disease and cancer . . . is a high priority.” Dr. Manson stated.

In an analysis of people in the VITAL study who developed an autoimmune disease, Hahn and colleagues found that taking a vitamin D supplementation for five years, with or without the use of omega 3 fatty acids, reduced the incidence of autoimmune disease by 22%.

For many people, ensuring adequate vitamin D levels means taking a daily supplement

at a dosage recommended by a health care professional.

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- Manson JE, Cook NR, Lee I-M, et al. Marine n-3 fatty acids and prevention of cardiovascular disease and cancer. *N Engl J Med.* 2019;380(1):23-32.
- Hahn J, Cook NR, Alexander EK, et al. Vitamin D and marine omega 3 fatty acid supplementation and incident autoimmune disease: VITAL randomized controlled trial. *BMJ* 2022;376:e066452

## Standing Frame Can Benefit People with MS and Impaired Mobility

It has been said that “sitting is the new smoking.” Indeed, prolonged sitting without sufficient exercise can be harmful over a long-term period. However, many people with disability due to multiple sclerosis (MS) find it hard to stand up or maintain a standing position. This includes people who use a cane or other device for mobility. Fatigue, muscle weakness, and spasticity may contribute to standing difficulties in people with MS.



A “standing frame” device provides standing support for a person who has problems with mobility, balance, or controlling the lower limbs or lower body. The benefits of using a standing frame may include:

- strengthening muscles
- stretching weight-bearing muscles
- enhancing breathing
- maintaining bone density

Researchers from the United Kingdom tested how a standing frame can help people who have MS. The researchers tested the device in 71 people with MS who had impaired mobility. People in this group brought the device home and were asked to use it for 30-minute sessions, three times a week while receiving physiotherapy support via phone. The results were compared with those for 69 people with MS who did not receive a standing frame. Participants recorded events (such as falls) in a diary and were evaluated at 20 weeks by health professionals.

After 20 weeks, the group using the standing frame had improvements in motor function, including better hip and knee strength. The number of falls was also lower in the standing frame group. While the overall long-term clinical benefits are unclear, the researchers

felt that the benefits of these devices that they observed should be further studied in people with MS.

“Individuals with progressive MS spend much of their day sitting, often with reduced ability to change position,” the authors stated. Although strong evidence shows that increased physical activity can improve mobility and minimize other health problems, up to 78% of people with MS do not participate in meaningful physical activity, they stated. Devices like the standing frame may help some people with MS to overcome barriers to physical activity.

#### Reference

Freeman J, Hendrie W, Jarrett L, et al. Assessment of a home-based standing frame programme in people with progressive multiple sclerosis (SUMS): a pragmatic, multi-centre, randomised, controlled trial and cost-effectiveness analysis. *Lancet Neurol.* 2019 Aug;18(8):736-747.



## MSMESSENGER

WHAT TO EXPECT ON THE NEXT NARCOMS SURVEY

As a refresher for those who complete your surveys online: you no longer need to go to the NARCOMS website to access your surveys, and you do not need a login 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 must save for use to access your partially completed survey. You also can enter your email address to have the return code emailed to you.

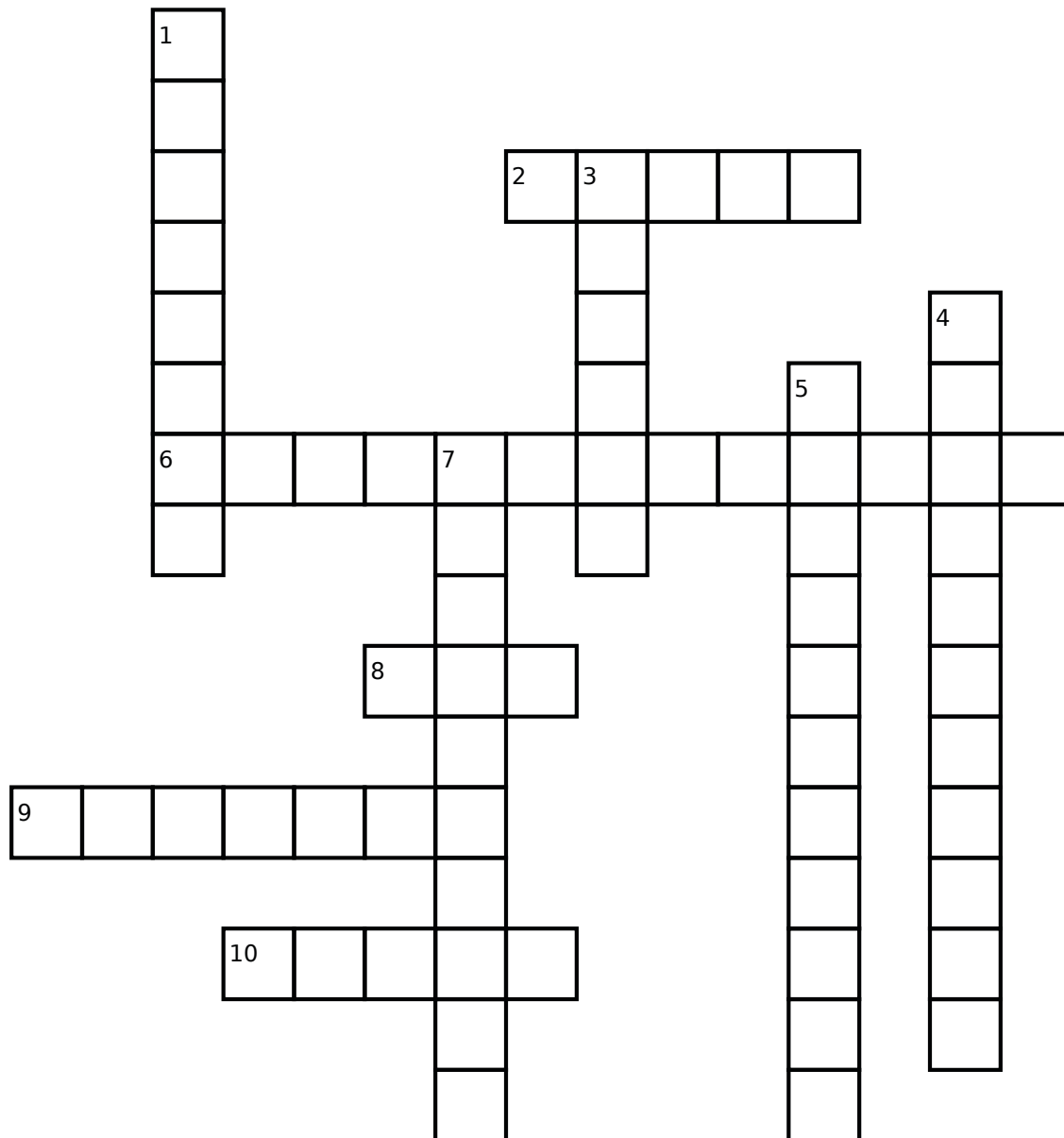
Please contact us if you have not received your Fall 2022 survey!

As always, you can update your contact information with us by email at [msregistry@narcoms.org](mailto:msregistry@narcoms.org) or by calling us at (214) 648-4583.

**The Fall 2022 survey is going on now!**

Please be sure to return your paper surveys if you have not done so yet. Thank you for your participation! The Fall 2022 survey will close in December 2022.

# Play **CROSSWORD**



**Down:**

1. this helps people stay healthy longer, even disabled people
3. body system that fights off infections
4. overlapping medical condition
5. form of MS that no longer has relapses
7. common but treatable comorbid condition in MS

**Across:**

2. name of study measuring vitamin D and fish oil benefits
6. device that helps people stand up longer
8. you lie in a "tube" for this brain imaging study
9. MS registry that uses surveys
10. virus that took over 2020

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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](mailto:MSRegistry@narcoms.org).



twitter: @narcoms  
instagram: @narcoms\_now

For more information on the CMSC visit [www.mscares.org](http://www.mscares.org)  
[www.NARCOMS.org](http://www.NARCOMS.org)