

## COVID-19 Outcomes in 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, or call toll free at 1-800-253-7884.



### Tell Us Your Thoughts!

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

**Call:** 1-800-253-7884 (toll-free U.S.)

**Email:** [MSRegistry@narcoms.org](mailto:MSRegistry@narcoms.org)

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

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For more information on the CMSC visit

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# DIRECTOR'S LETTER

Dear NARCOMS Now Readers:

In this issue of *NARCOMS Now*, we focus on COVID-19 outcomes in people with MS, new technologies that may be used to treat MS, new therapies being approved for use, digital assets to assist in mobility, and information concerning Medicare coverage for people with MS.

In the Feature Focus, Dr. Amber Salter (Data Coordinating Center Director for NARCOMS) provides some clarity on the effect of COVID-19 infection in people with MS. Advanced age, cardiovascular disease, and obesity are some comorbid conditions that increase the chance of hospitalization, death, or both in people with MS who also have COVID-19 infection. Some information is provided concerning the association between the severity of COVID-19 infection and disease-modifying therapies.

In a Special Focus, we interview Shalini Lynch, PharmD, an expert on healthcare finance topics. Her answers to our questions provide important information concerning Medicare coverage for MS therapies. In the SnapShot, we examine the types of health insurance coverage that NARCOMS participants consider important.

In the MS News sections, we examine the application of the same the vaccine technology used to develop the initial COVID-19 vaccinations for possible treatment of MS, the latest disease-modifying therapy for MS to be approved by the U.S. FDA, and a mobile app that assists people with mobility limitations.

We thank you for your continued participation in the NARCOMS registry! Your involvement in this registry is critical in advancing our knowledge of MS.



Ruth Ann Marrie,  
MD, PhD

Sincerely,

A handwritten signature in black ink that reads "Ruth Ann Marrie".

Ruth Ann Marrie, MD, PhD  
Scientific Director, NARCOMS



## Exploring COVID-19 outcomes in People with MS – The COViMS Registry

When COVID-19 spread around the world, people with conditions like multiple sclerosis (MS) wanted to know how they might be affected. Are people with MS more susceptible to COVID-19? More likely to become seriously ill? Do the disease-modifying drugs that people take for MS have any effect on the severity of COVID-19 infection, or on the safety or effectiveness of the vaccine?

Registries like NARCOMS are a valuable way to find out about how COVID-19 affects people with this disease. The information is important for researchers who are working on COVID-19 vaccines and treatments. It is also important to help inform people who are living

with MS. Early in the course of the pandemic, a new registry named COViMS (COVID-19 Infections in MS) was established so healthcare professionals could report cases of COVID-19 in people with MS. Using data from this program, researchers investigated factors associated with severe outcomes in North Americans with MS and COVID-19 infection. The research report was published in *JAMA Neurology* in March 2021. The study's lead author was NARCOMS' Coordinating Center Director Dr. Amber Salter with NARCOMS' Managing Director Dr. Robert Fox as co-author.

Between April 1, 2020, and December 12, 2020, healthcare professionals reported a total of 1,626 cases of COVID-19 affecting

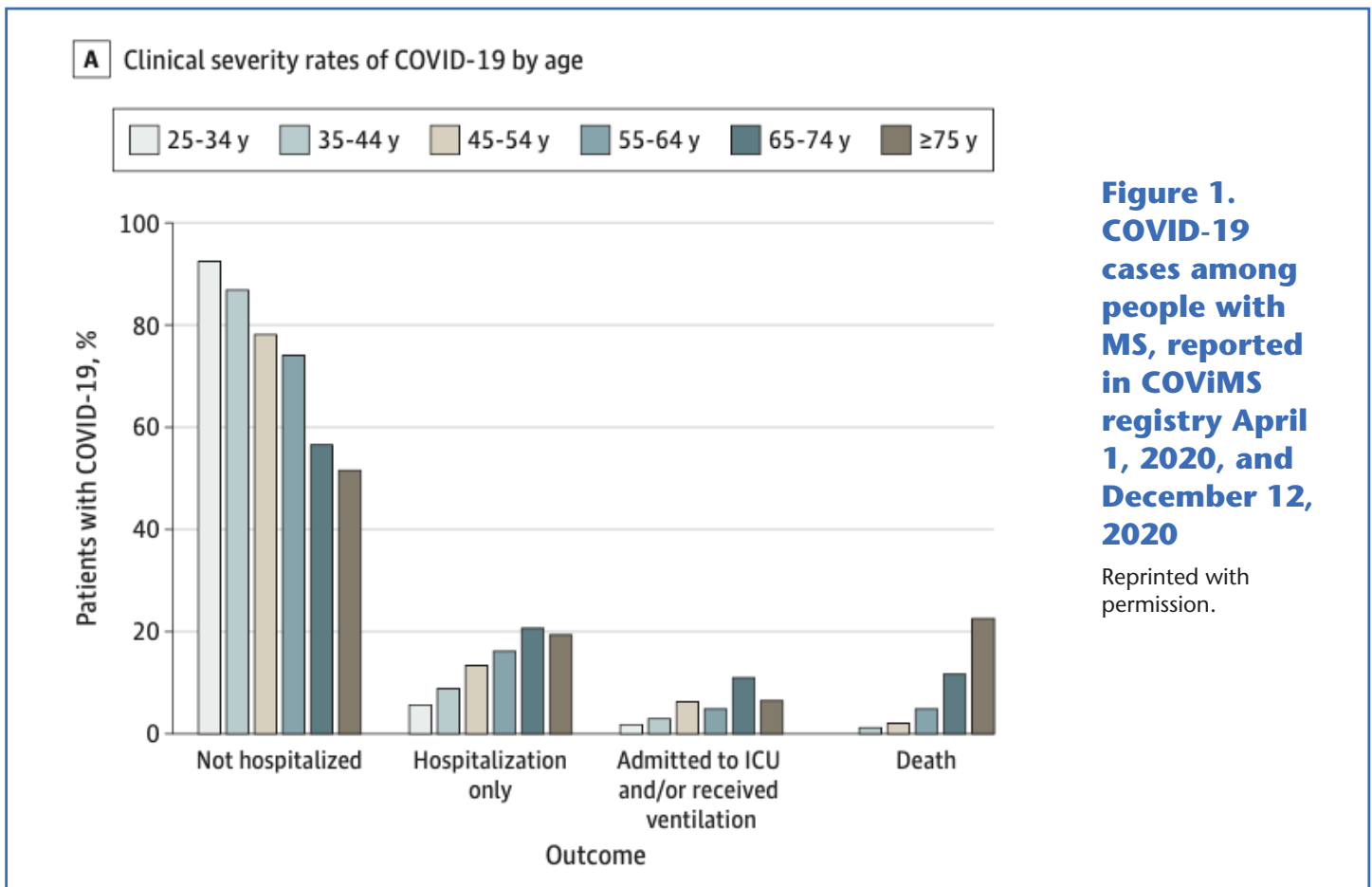


people with MS. About three-quarters of cases occurred in women, and about 80% had relapsing-remitting MS. The average age was 47.7 years, and about half had at least one other medical condition (comorbidity).

Similar to what was seen in the general population, older age was a major risk factor for being hospitalized or dying from COVID-19 for people with MS (**Figure 1**). Death rates were low overall (54 deaths among 1,626 cases, or 3.3%) and occurred mostly in persons aged 75 years or older. This is higher than the reported U.S. death rate of 1.8% for that same time period, in part because the U.S. rate included all COVID-19 cases, including children, and healthcare professionals may only have information on patients with more serious

COVID-19 infections to report.

“As in the general population, we found that having a complicating medical condition increased the risks for a serious COVID-19 outcome,” Dr. Salter said. People with MS and cardiovascular disease had a 90% increased risk for being hospitalized due to COVID-19 and triple the risk of dying from COVID-19, versus those who did not have cardiovascular disease. Having high blood pressure increased risks for COVID-19 deaths by three-fold, while having diabetes was found to increase the risk of hospitalization for COVID-19. Morbid obesity is another condition associated with poor COVID-19 outcomes in all populations. In people with MS, morbid obesity was associated with 68.5% increased odds of hospitalization



**Figure 1. COVID-19 cases among people with MS, reported in COViMS registry April 1, 2020, and December 12, 2020**

Reprinted with permission.





and an almost three-fold increased risk for ICU admission, and an almost three-fold increased risk for ICU admission to treat severe COVID-19.

Based on other population-based studies, having MS, on its own, does not appear to increase the risk for having a more serious course of COVID-19, Dr. Salter explained. “The findings from COViMS are consistent with what we have seen in other MS and COVID-19 registries across the world.” This suggests that the changes in the immune system related to MS do not appear to make COVID worse. However, people with advanced MS who were nonambulatory (unable to walk) did have a higher rate of severe COVID-19 outcomes. Compared with people with MS who were fully ambulatory, this included greater risk for hospitalization, ICU admission and/or need for ventilator, and significantly increased risk of death from COVID-19.

Some racial differences were noted in the

registry. The racial/ethnic breakdown of reported COVID-19 cases was:

- White (non-Hispanic) 61.5%
- Black 20.8%
- Hispanic/Latinx 11.7%

Compared with White race, Black race was associated with an increased risk for admission to the ICU or need for a ventilator. The COViMS registry did not show an increased risk of death from COVID-19 among Black individuals with MS. Again, these results are similar to those of other studies from the U.S. population, which did not find increased mortality in Black patients with COVID-19 after adjusting for other risk factors. Dr. Salter noted, “We do not understand why we see this effect, but additional uncollected information, such as essential worker status, could explain some of the racial differences we are seeing. However, it does not seem as though this information would completely explain the differences we

observed.”

The study also examined the potential effects of MS medications. Some medications make it harder to fight infections by altering some immune system functions. The COViMS study showed that people taking MS therapies that deplete B cells (these include ocrelizumab and rituximab) had a higher risk for hospitalization due to COVID-19. Use of a corticosteroid around the time that COVID-19 infection started doubled the risk for hospitalization from COVID-19 and also was associated with a four-fold increased risk of death. “Individuals with MS should discuss the potential impact of their MS medications with their healthcare provider, since every case is highly individualized,” Dr. Salter stressed. Overall recommendations from the U.S. Center for Disease Control and Prevention for reducing the risk for COVID-19 infection and serious illness are summarized in **Figure 2**.

As we have moved through the pandemic, medical professionals and researchers have learned more about treating COVID-19 and preventing a severe course of illness. The COViMS registry will continue to collect more data on COVID-19 infection in people with MS, Dr. Salter said. The new data collected should start to reflect these improvements in care. “Additionally, we will continue to study COVID-19 in people with MS. We will look more closely at certain subpopulations in an effort to provide information about how to deliver the best care for people with MS in general and in at-risk groups,” she concluded.

**Figure 2.**

## Recommendations from the CDC on COVID and chronic health conditions

If you are older or have serious health conditions, preventive measures for COVID-19 are especially important. These include **vaccination**, wearing a mask, social distancing, practicing hand hygiene.

Continue your medicines. Do not change your treatment plan without talking to your healthcare provider.



Follow your current treatment plan (medications, testing, nutrition, and exercise recommendations) to keep your medical condition under control.

Learn about stress and coping. You may feel increased stress during this pandemic. Fear and anxiety can be overwhelming and cause strong emotions.



**Do not delay getting emergency care for your medical condition because of COVID-19.**



Contact your healthcare provider if you have any concerns about your medical conditions or if you get sick and think that you may have COVID-19. If you need emergency help, call 911 right away.

When possible, keep regular healthcare appointments. Check with your provider about safety precautions for office visits and ask about telemedicine or remote healthcare visit options.



For more information, visit [www.CDC.gov](http://www.CDC.gov)

[www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/prevention.html](http://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/prevention.html)  
[www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html](http://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html)



# SNAPSHOT

WHAT WE CAN LEARN FROM NARCOMS SURVEYS

## NARCOMS Survey on Health Insurance

**H**ealth insurance plays an important role in the overall healthcare landscape faced by most NARCOMS participants.

Navigating appropriate health insurance coverage can be a daunting experience, especially when moving from coverage through a private or commercial plan to Medicare. In this issue, we have a Special Focus to provide some information to our readers to help inform their selection of Medicare and Medigap coverage. Shalini Lynch, PharmD, Health Sciences Associate Clinical Professor in the Department of Clinical Pharmacy at the University of California San Francisco, an expert on healthcare finance topics, answers some questions concerning Medicare coverage for people with MS.

In every NARCOMS survey, we ask NARCOMS participants several questions about insurance coverage choices. Results from the recent Fall 2020 survey showed that most NARCOMS participants (98.9%) currently have health insurance and only slightly fewer (98.4%) have maintained coverage over the past 6 months. These rates of healthcare coverage surpass those reported by the U.S. Census Bureau for 2019, which reported that 92% of the U.S. population had some form of health insurance coverage for all or part of 2019.<sup>1</sup> Similarly, while 1.6% of NARCOMS participants reported having no health insurance coverage, 8% of the US population was reported to lack healthcare insurance. Lack of health insurance in the U.S. population was highest (11.1%) in adults aged 19 to 64 years, followed by

### MEDICARE VS MEDICAID

**Medicare** is operated by the federal government. You may be eligible for Medicare benefits if you are 65 or older, under 65 and permanently disabled, or have kidney disease or ALS, for example. People with multiple sclerosis can qualify for Medicare coverage before age 65 if they are permanently disabled.

**Medicaid** is operated by individual states and provides health coverage for some low-income people, families and children, pregnant women, the elderly, and people with disabilities, including some people living with MS. However, there is significant variation between states in eligibility and coverage.



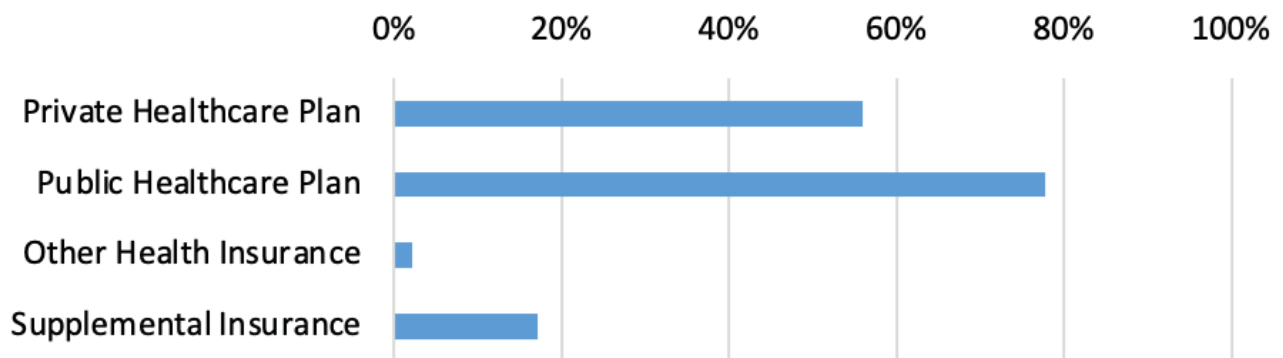
children under the age of 19 (5.2%) years and adults aged 65 years and older (1.1%). For NARCOMS participants, 2.2% of those under the age of 19 years reported no health



insurance coverage, followed by 1.9% of participants 19-64 years old and <1% of those greater than 65 years old. Together, these results indicate that NARCOMS participants have a higher rate of health insurance coverage than that of the average U.S. citizen.

As shown in **Figure 1**, more NARCOMS participants (72%) are covered by a U.S. public healthcare plan (Medicare, 60.4%; Medicaid, 7.4%; Veterans Administration, <4.5%) than by private/commercial insurance (56%). The type of healthcare coverage held by NARCOMS participants may be attributed to age (the median age of NARCOMS participants is 64.0 years old), and may also be influenced by specific need, in particular the need for Supplemental Insurance. The types of insurance reported by NARCOMS participants are not mutually exclusive and more than one type of insurance may be carried by an individual.

Survey Question: What type of health insurance do you have?



**Figure 1.**

<https://www.census.gov/content/dam/Census/library/publications/2020/demo/p60-271.pdf>



## MEDICARE COVERAGE FOR MS THERAPIES

**M**edicare is a healthcare payment program that covers U.S. citizens over age 65 years. People under age 65 years who receive Social Security Disability Insurance (SSDI) benefits can also receive Medicare benefits. Shalini Lynch, PharmD, Health Sciences Associate Clinical Professor in the Department of Clinical Pharmacy at the University of California San Francisco, is an expert on healthcare finance topics. *NARCOMS Now* asked Dr. Lynch to answer some questions about Medicare that apply to people with multiple sclerosis (MS).

**Medicare coverage can be confusing. What aspect do you think people struggle with most?**

Many patients can become confused about what each part covers, especially if they are new to receiving Medicare. Medicare benefits are divided into Plans A, B, C, and D (see **Table 1**). Part D is the main program that covers prescription medications. However, Part B covers the cost of some medications if they require administration by a healthcare provider.

**What is a Medicare Supplement, or Medigap?**

Medigap is a supplemental insurance policy that helps to fill any “gaps” not covered by Medicare. Medigap insurance is sold by private companies. Medicare pays for much,



**Shalini Lynch,  
PharmD**

but not all, of the cost for covered health care services and supplies. The gap policy can help pay some of the remaining costs, such as co-payments, co-insurance, and deductibles. People with MS may want to consider purchasing a supplement to assist with the co-insurance for drugs billed to Part B.

**Table 1. What Services does Medicare Cover?**

|                             |  |
|-----------------------------|--|
| Part A                      | Inpatient hospital care, nursing homes, home health, hospice care  |
| Part B                      | An optional plan with a monthly charge. Covers care provided by doctors and other healthcare providers; long-term home health care; durable medical equipment; outpatient hospital services; and physical, speech, and occupational therapy. |
| Part C (Medicare Advantage) | Private health plans that offer at least the same benefits as parts A and B. These plans have different rules, costs, and coverage restrictions.   |
| Part D                      | Prescription drug coverage for some drug therapies   |

### **What is the most important thing that people with MS need to know in terms of Medicare coverage for MS disease-modifying therapies (DMTs)?**

People with MS should ask their healthcare provider or pharmacist which DMTs are billed to Part B and which are billed to Part D. A Medicare supplement plan and/or a co-pay assistance program may be needed to cover the costs of these drugs. For Part D drugs, patients should review all the plan options available to them during the open enrollment period to review their coverage options and how much co-insurance they are expected to pay.

### **For More Information**

#### **Medicare.gov: What's Medicare Supplement Insurance (Medigap)?**

<https://www.medicare.gov/supplements-other-insurance/whats-medicare-supplement-insurance-medigap>

#### **National MS Society: FAQs about Medicare**

<https://www.nationalmssociety.org/Living-Well-With-MS/Work-and-Home/Insurance-and-Financial-Information/Health-Insurance/Medicare/FAQs-about-Medicare#question-Can-People-with-MS-and-Other-Long-Term-Illnesses>



# MS MESSENGER

WHAT TO EXPECT ON THE NEXT NARCOMS SURVEY

## **Happy Summer!**

Hopefully you are all able to stay cool as possible as the temperatures rise. As the spring surveys continue to be returned, we are hard at work on the fall survey for October. ***Don't forget to return your spring surveys.***

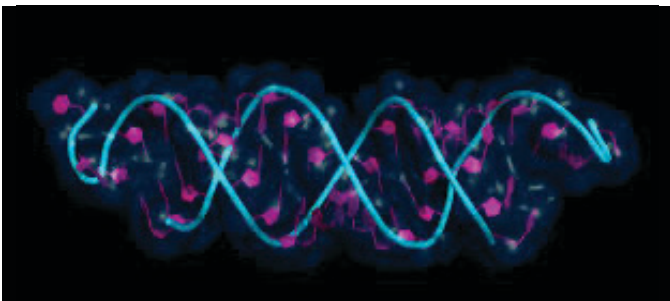
We are always looking for ways to make the survey easier and faster to complete while maintaining the integrity of the data we collect. With the approval of new immunotherapies, our current question in

the survey has become outdated. Participants have contacted us to let us know they have found that section of the survey confusing. We want you to know that we listen to your concerns, and we plan to make changes to the format of the immunotherapies or disease modifying therapies (DMT) questions. Our goal is to collect this very important information as easily as possible. We know some of you do not take DMTs, so we want to know that, too!



## Gene Technology Used in COVID Vaccines Studied as Possible Avenue for Treating MS

Could technology used to develop some COVID-19 vaccines be useful for treating multiple sclerosis (MS) in the future? This novel idea is being explored by a group of investigators from Johannes Gutenberg University in Mainz, Germany. Messenger RNA (mRNA) is a code that instructs the cells to make a particular protein. In this research project, mouse models of MS were injected with mRNA to instruct the immune system



to target inflammatory processes involved in the development of MS. The goal is to coax the immune system to tolerate the antigens that lead to an attack on myelin (the coating around the nerves that is damaged in people with MS), without affecting normal healthy immune responses. After the mice were treated with the modified mRNA, they had less severe disease. Their cells showed reduced inflammation and more regulatory cells that help fight attacks on the myelin. Normal healthy immune responses were unchanged.

Various forms of mRNA are being explored as therapies for diseases in humans. This research uses technology developed by BioNTech, the company that developed a COVID-19 vaccine with Pfizer Inc. The group hopes that using modified mRNA to deliver coded instructions for myelin proteins will lead to future new therapies for people with MS. The mouse model of MS is different from immune processes that occur in human MS, so these ideas need further study before they can shift to clinical trials in humans.

**Reference:** Krienke C, Kolb L, Diken E, et al. A noninflammatory mRNA vaccine for treatment of experimental autoimmune encephalomyelitis. *Science*. 2021 Jan 8;371(6525):145-153.

## New Oral MS Therapy Approved by FDA

Ponesimod is the latest disease-modifying therapy to be approved by the U.S. Food & Drug Administration (FDA) for the treatment of relapsing forms of multiple sclerosis (MS). Ponesimod (Ponvory®), is an oral drug taken once daily that is in the category of sphingosine 1-phosphate receptor (S1-P) modulators. This category also includes two previously approved MS therapies, fingolimod (Gilenya®) and siponimod (Mayzent®). These drugs work by preventing some immune cells from leaving the bloodstream and entering the central nervous system where they can attack and damage brain and spinal tissue.

Ponesimod’s approval was based on a clinical trial (OPTIMUM) in 1,133 people with relapsing MS that compared it directly with teriflunomide (Aubagio®), another oral MS drug. Results of this trial include:

- 30% greater reduction of annual relapse rates compared to teriflunomide (14 mg). Approximately 71% of ponesimod-treated patients had no confirmed relapses compared to 61% of the teriflunomide group;
- Fatigue, as measured by a new fatigue questionnaire, was less in ponesimod-treated patients compared to those treated with teriflunomide;
- Gadolinium-enhancing (Gd+) brain MRI lesions were reduced by 59%;
- New or enlarging T2 brain MRI lesions were reduced by 56%;
- Data on disability worsening was comparable between the two drugs. Most study participants (9 out of 10) did not have worsening of disability at 3 months.

Ponesimod adds another treatment option to people with relapsing MS. Screening steps needed before starting the therapy are similar to those needed for fingolimod and siponimod. These include liver function tests, cardiac tests, and eye tests. Unlike with fingolimod, a monitoring period immediately after receiving the first dose is not required for most people starting ponesimod, but may be needed for some patients with certain heart conditions.

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**Reference:** Kappos L, Fox R, Burcklen M, et al. Ponesimod compared with teriflunomide in patients with relapsing multiple sclerosis in the active-comparator phase 3 OPTIMUM study. *JAMA Neurol.* 2021; March 29. Free article: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8008435/>

## Innovative Mobile App and Web Site Help People with Mobility Limitations Locate Accessible Places

Accessible public locations are essential for anyone with limited mobility. However, information about whether a place is or is not accessible for those with disabilities is often unavailable, out of date, or inaccurate. A new mobile app and web platform called AccessNow allows users to pinpoint the location of accessible venues around the world (**Figure 1**). These may include retail stores and restaurants, public facilities, sports venues, transportation hubs, etc. The Community function allows users to rate the accessibility of locations they have visited (**Figure 2**).

The Founder and CEO of AccessNow, Maayan Ziv, is a photographer and activist living with muscular dystrophy. “AccessNow grew from my personal experience navigating around Toronto,” she said. “While accessibility has come a long way since then, we know there’s so much more to do to achieve equality and inclusion.” The company received a Novartis Innovation Prize for Assistive Tech for MS from Novartis Canada. The goal of this prize is to spur investment and dialogue across the many needs of people living with MS, and other people living with mobility-limiting conditions.



**Figure 1.**



**Accessible**

A green pin on our map represents an accessible location. These are places

without barriers. Experiences may vary from person to person, but we generally say that accessible places are those that you can get in with ease and “party no problem.”



**Partially Accessible**

A yellow pin on our map represents a location that is partially accessible.

Yellow locations often have alternative entrances or limited access within the space, such as steps inside or narrow hallways. Not everything about these places is barrier-free.



**Not Accessible**

A red pin on our map represents a location that is not accessible. Find a red pin on

our map? Why not post about it and let’s make change happen. The more awareness about inaccessible places, the closer we are to breaking barriers.

**Figure 2.**



**Search**

Search for specific locations with the accessibility features you require



**Rate**

Join our community by rating new locations on our map with tags and descriptions



**Filter**

Filter the map to discover places with specific accessibility features



**Discover**

Browse our interactive map to discover accessible places around the world

A Novartis Canada spokesperson stated that the AccessNow app achieves the prize’s goal to “identify and embrace technology that aims to improve the mobility, accessibility, and activities of daily life for individuals living with mobility-limiting conditions.”

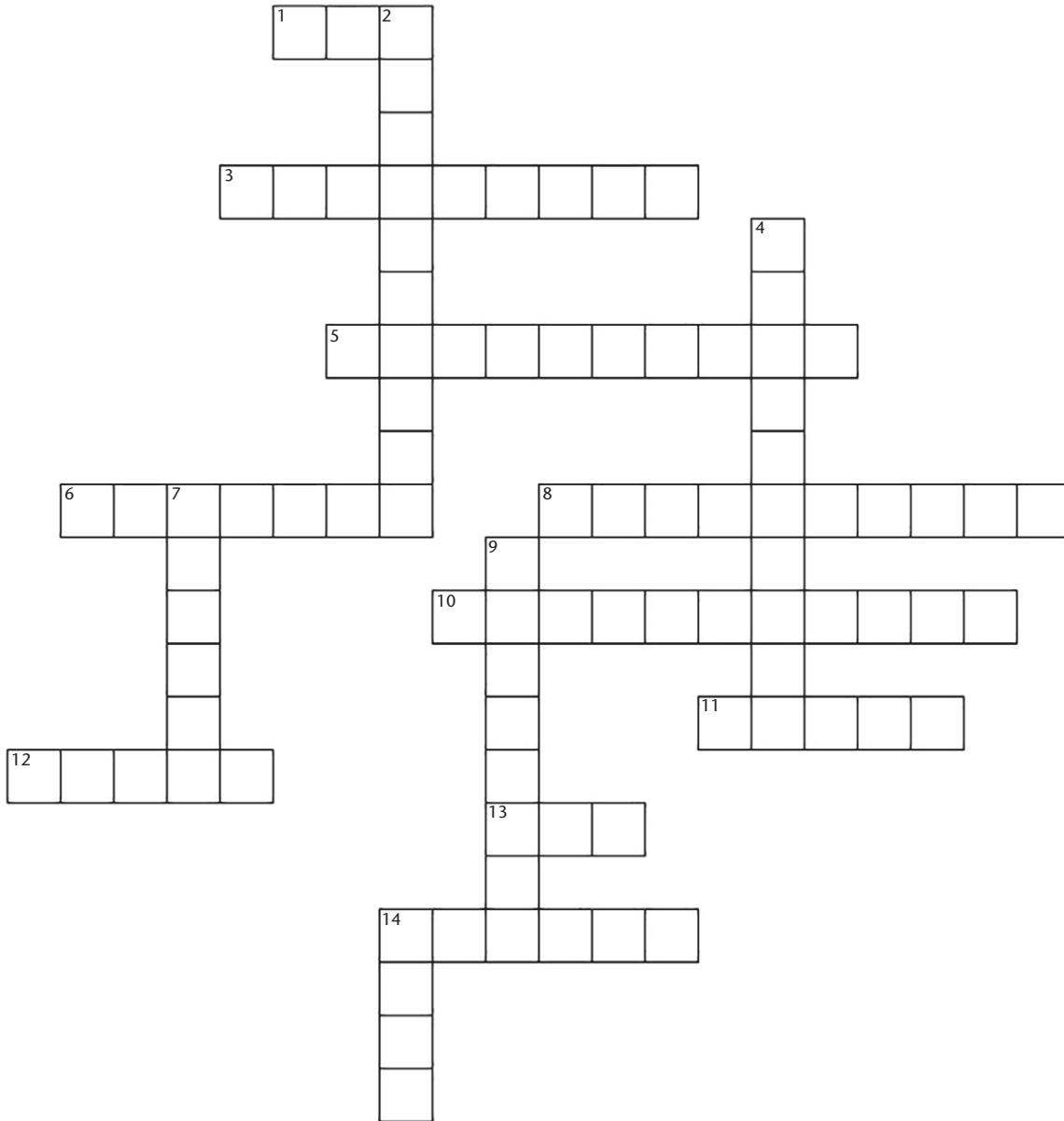
Innovations that improve mobility can help make everyday life more manageable for people living with MS and help keep them connected to their lives and communities.

For more information about the app, visit <https://accessnow.com/>

Please be on the lookout for more information about the free Consortium of Multiple Sclerosis Centers (CMSC) Patient Forum coming in October. This is a special educational program for people living with or affected by MS. Participation is available in-person and virtually. To find out more, go to <https://cmscscholar.org/2021-annual-meeting/> and **click on the Patient Program tab**. You can submit questions to researchers and healthcare professionals before the meeting. If you are in the Orlando, Florida area and would like to attend in person, a link to the registration can be found on the website.

# Play **CROSSWORD**

## MS and COVID Updates



### ACROSS

1. Messenger \_\_\_\_: Technology used to develop COVID vaccines
3. Name of new MS drug approved in 2021
5. Social \_\_\_\_, term for staying 6 feet or more apart
6. Best bet for preventing infection with COVID virus
8. Term that means able to walk
10. Continue to take these, or speak with your doctor before discontinuing
11. Medicare Part D covers the cost of many of these
12. Another word for overweight

13. Biggest risk factor for death or serious illness from COVID

14. Nerve cell coating that is damaged in MS

### DOWN

2. User-friendly for people in a wheelchair
4. Device used in hospital to assist with breathing
7. Name of registry to report cases of COVID-19 in people with MS
9. Government program that pays for healthcare for older or disabled individuals
14. Face covering commonly worn during pandemic

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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 at 1-800-253-7884 (toll-free U.S.) or via email at [MSRegistry@narcoms.org](mailto:MSRegistry@narcoms.org).



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