

# May 2022 Newsletter



## The Rising Cost of MS Care

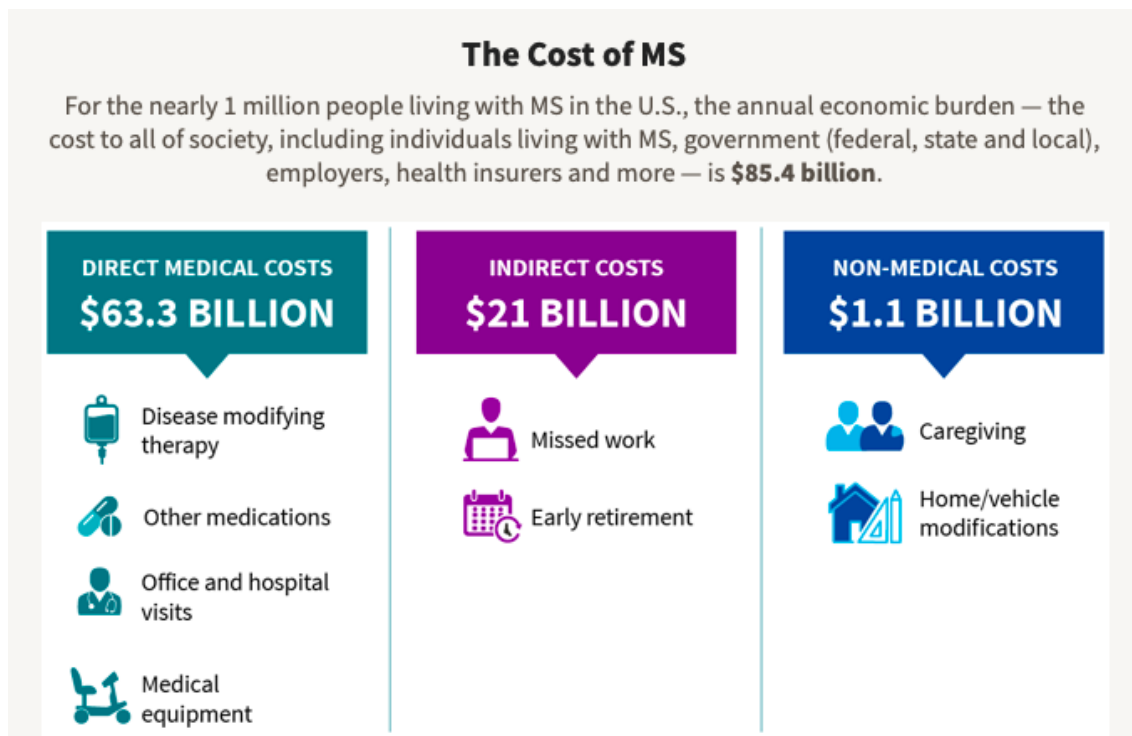
According to the [National MS Society](#) (the Society), nearly one million people are living with MS in the United States. This is more than double the previous estimate of 400,000 individuals with the disease. Chronic illnesses like MS are expensive, not just because of medical bills. The disease's debilitating effects have the potential to cause cognitive and physical decline. Mounting disability often prevents people with MS from working or limits their employment opportunities and consequently reduces their earnings. In addition, many family members need to leave their employment to be caregivers. In recent years, a number of new treatment options have become available to help slow the progression of the disease. In light of the new prevalence estimate for MS and the availability of so many new disease modifying therapies, the Society recently sponsored [research](#) to investigate the present and future cost of MS for families living with the disease. The study also sheds light on the disease's impact on the U.S. economy. As anyone living with MS can attest to, results confirm that the disease is very expensive.



For the purposes of this study, investigators divided the cost of MS into three categories: direct medical costs (for example, medications and medical appointments), indirect

medical costs (such as job loss or lost productivity at work) and non-medical costs like caregiving and expenses for necessary home or vehicle modifications. Data regarding the direct medical cost of MS was obtained from Medicare and insurance claims of 10,589 people with MS and 105,893 people without MS who were matched for age and sex. The research team calculated the direct medical cost per person for three consecutive years (2017 – 2019) and then determined average expenses for one year. Information regarding indirect and non-medical costs was obtained via a survey, which was administered to 946 study participants with MS.

Data shows the prevalence of MS increases with age. In 2019, the majority of the MS population (50%) was between 45 and 65 years old. While the prevalence of MS in people younger than 45 years was low, this age group represented the second largest group in the MS population (nearly 30%). Results confirm that the disease occurs more often in females than males, with females representing 74% of the total MS population. According to the study, the average total cost of living with MS was \$88,487 per year. The annual economic burden, or cost to all of society, including individuals living with MS, government, employers, health insurers, etc., was \$85.4 billion per year. Data trends show that, over the next two decades (by 2039), the prevalence of MS in the United States will increase to 1.1 million people, and the economic burden will soar to \$105.5 billion.



Graphic from the [National MS Society website](https://www.nationalmssociety.org/)

Researchers concluded 74% of the total economic burden of MS (\$63.3 billion) was attributed to its direct medical costs. One quarter of this figure (\$21 billion) was related to its indirect costs and the remaining one percent (\$1.1 billion) was due to its non-medical costs. Further breakdown of direct medical costs showed that disease-modifying therapies (DMTs) were the biggest expense, representing 64% of the total. The remaining direct medical costs were other prescription medications (often used as



symptomatic therapies), physician services, hospitalization and long-term care facilities. The main contributors to indirect costs were premature death (38%), lost productivity (28%) and inability to work (26%). The top non-medical costs included healthcare not covered by insurance, caregiving and necessary home or vehicle modifications.

At an individual level, results show the medical costs associated with living with MS in 2019 were \$65,612 more each year than medical costs for people without MS. The largest proportion of this cost was for medications. The actual amount spent per year varied from person to person based on many factors, including use of DMTs, individual needs and health insurance coverage. Data analysis revealed the average cost for an MS caregiver is \$4,333 per year. It's important to note that indirect and nonmedical costs were determined based on survey responses and, thus, relied on respondents' memory. Therefore, some costs may have not been accurately reported.

Living with MS and struggling with its symptoms is stressful in and of itself. Dealing with the costs of healthcare and MS treatments can add to that stress for those living with the disease. As we discussed in our [September 2020 newsletter](#), a number of financial and patient assistance programs are available to help with the cost of MS medications. In addition, the National MS Society offers a number of resources to help manage the expenses of living with MS.



## National MS Society resources:



Financial and Insurance Information



Health Insurance Appeals and Exception Requests



Employment Rights / Requesting Accommodations



Ask an MS Navigator

The National MS Society study shines a spotlight on the high price tag that MS carries for the U.S. economy and the real impact these costs have on those living with the disease. A growing number of DMTs are available which generally reduce the number of relapses an individual may experience (resulting in longer disability-free periods). This, in turn, helps to reduce the indirect and non-medical cost of MS overall. However, nearly two-thirds of the direct cost of the disease is related to the cost of these medications. While there are financial assistance programs available to help, this study highlights the importance of interventions to control the rising cost of DMTs. Other programs are available to ease the cost of living with MS. The Society's recent study suggests that adding assistance to these services for things like long-term care, occupational training and employment support could serve to reduce the economic burden of MS and further improve the lives of those living with the disease.

## Beat the Heat with MS

The vast majority ([60 - 80%](#)) of people with MS find that even a small rise in body temperature can cause their symptoms to worsen. Warming the skin often has the same effect. This can be due to many factors, including the weather, hot showers, fever, exercise, or even a heavy meal. As a matter of fact, in the 19<sup>th</sup> and 20<sup>th</sup> centuries (before modern diagnostic procedures), this experience was used to determine whether or not a person had MS. Doctors would put individuals suspected of having MS in a hot bath for a period of time and observe how they acted when they got out. If they exhibited worse neurological symptoms as a result, they were diagnosed with MS.



The correlation between heat and the worsening of MS symptoms is also known as [Uhthoff's Phenomenon](#), named after German ophthalmologist Wilhelm Uhthoff. In 1890, he first noticed that people suffering with optic neuritis would get worse when they exercised. It was later determined that exercise was not the cause, rather that it was the resulting heat and rise in body temperature. Uhthoff's Phenomenon occurs due to demyelination of nerve cells in the brain and spinal cord, which slows down the conduction of nerve signals. Heat slows this process even further. As a result, the body doesn't respond the way it should to changes in temperature. Lesions in the [hypothalamus](#) (the part of the brain that regulates the body's temperature) also inhibit sweating or shivering responses which keep an individual comfortable when the mercury rises or falls.

While Uhthoff's Phenomenon originally focused on visual symptoms, [research](#) has since shown that heat exacerbates other MS symptoms, too. Sometimes, new and unfamiliar symptoms can appear. Exacerbations of this kind are usually temporary. Heat does not cause more damage to



the nerves, and symptoms improve once the person has cooled down. Just as everyone's MS experience is unique, heat tolerance can differ from person to person. The type and severity of symptoms varies, as does the length of time it takes to recover after cooling down. Some feel worsening symptoms at much lower temperatures and with much less activity.

Heat intolerance can be very limiting for people with MS and have a profound effect on their quality of life. There is currently no drug treatment available, however there are a number of simple ways to cool down.

### Tips to keep the body cool:



**Plan Your Day.** Schedule activities at times when the sun is not at its peak.



**Block the Sun.** Keep an umbrella handy for shade, if needed.



**Dress For the Heat.** Wear lightweight, loose, breathable clothing.



**Stay Hydrated.** Research shows drinking cold water helps people with MS exercise more.



**Keep Cool Drinks Available.** Store pre-filled water bottles or pitchers in the fridge.



**Explore Frozen Alternatives.** Eating ice chips and popsicles can help.



**Try Meal Prep.** The kitchen can heat up quickly, so plan ahead as much as possible.



**Eat Light.** Instead of heavy meals, opt for salads, no-bake dishes and fresh fruit.



**Use a Spray Bottle.** Try spritzing with water when the temperature rises.

A wet washcloth or bandana held to the face or draped along the back of the neck is another way to beat the heat. To keep one handy, they can be stored in individual resealable bags in the refrigerator or freezer. A number of [cooling products](#) are available that provide relief in a similar fashion. For those that get hot at night, a [cooling pillow](#) may help. Cooling vests are another popular option. These vests vary from simple designs that use ice packs to more complex ones that require batteries. Depending on the product, the cooling effect can last from a few hours to several days. As the name implies, [ice pack vests](#) use re-freezable ice packs that are put into internal compartments. [Evaporative](#) or [chemical](#) vests use water or chemical reactions to wick away the heat. Evaporative vests work best when humidity levels are low. [Active cooling vests](#) use motorized devices to stay cool for a longer period of time. Some require both water and ice. These are the most effective at cooling the body but can be bulky. A number of non-profit organizations provide cooling vests at no cost to people with MS that qualify, including the Multiple Sclerosis Association of America's [Cooling Distribution Program](#) and the Multiple Sclerosis Foundation's [Cooling Program](#).





## Tips to keep the environment cool:



**Adjust the thermostat** to maximize comfort.



**Stay in air conditioning** during periods of extreme heat and humidity.



**Find a fan.** Traditional fans work by evaporating sweat. **Misting fans** add moisture for extra cooling.



**Close curtains or blinds** to help keep rooms cool.



**Light with LEDs.** They put out a fraction of the heat, last longer and use less energy.



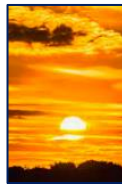
**Pull the plug.** Gadgets and devices create heat, even when not in use. Unplug them before going to bed.

Exercise helps to improve balance, strength, mood, and overall health for everyone. However, as mentioned above, it can also raise core temperature and briefly worsen symptoms for people with MS.

## Ways to exercise safely:



**Pick a Good Location.** Exercise in an unheated pool or a cool environment.



**Select Your Timing.** If exercising outside, pick cooler times of the day, usually early morning or evening.

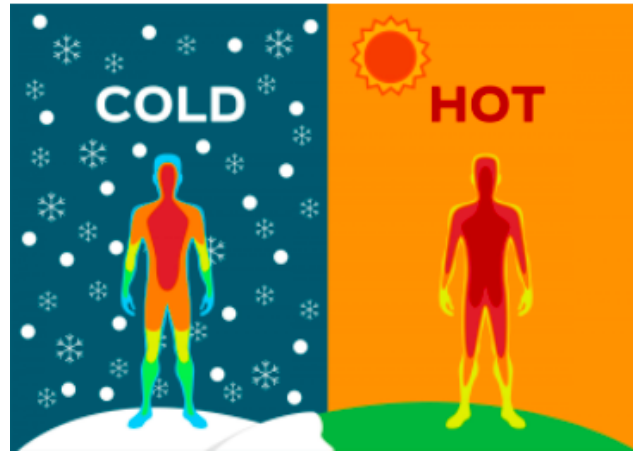


**Choose the Right Clothing.** Don't wear too many layers, even if it's cold.



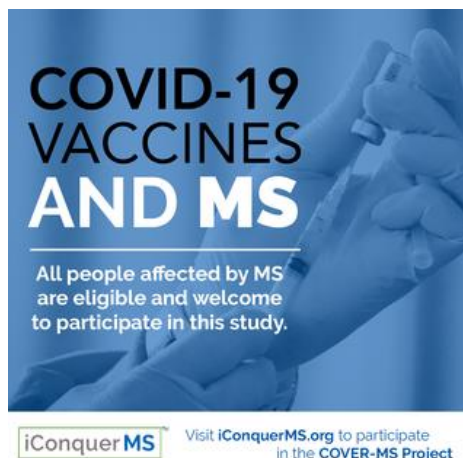
**Be Sure to Cool down.** Take a cool bath or shower after exercising or exposure to a hot environment.

There are plenty of ways to keep cool, which may help people with MS manage some of their symptoms. When using any strategy to cool down, however, moderation is key. Although heat sensitivity is most common, about [20%](#) of people with MS experience worsening symptoms due to cold temperatures (especially spasticity). It is essential that individuals sensitive to changes in temperature work with their healthcare team to develop best practices to control their body temperature and try to avoid either extreme.





## May 2022 iConquerMS Spotlight



### Coming soon to COVER-MS: Antibody analyses and new survey topics!



Did you know about the new developments for the COVER-MS study of COVID-19 vaccines in people with MS?

**Antibody analyses:** In partnership with Quest Diagnostics, we're launching a sub-study of COVER-MS to analyze the immune response to COVID-19 vaccines in people with MS. We'll be inviting 300 COVER-MS participants living in the US to donate blood samples every 6 months for the next 2 years. Participants will receive their COVID-19 antibody results in return.



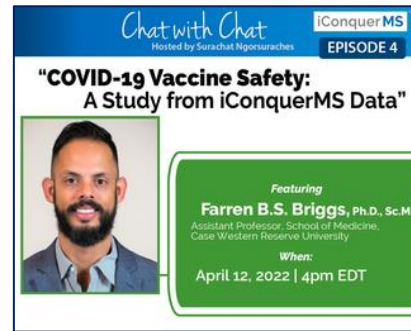
If you are interested in potentially participating in this study, **please log into [iConquerMS](https://iConquerMS.org) now, click on "Participate in the COVID-19 Vaccination Study" and make sure your vaccination information is up to date, including any booster doses.** We'll be selecting participants for this sub-study based on information previously provided in COVER-MS and will share more details soon.

**New surveys and analyses:** Thank you to those who provided ideas for COVID-19 topics that could be studied further through COVER-MS. We're developing new surveys and planning new analyses to explore these topics, including:

- Long COVID
- Access to Evusheld (COVID-19 preventive therapy)
- Breakthrough COVID infections
- Impact of COVID-19 vaccines on MS symptoms

We'll be in touch in a few weeks about these new topics and analyses – stay tuned!

**Chat with Chat:** In the most recent "Chat with Chat" webinar, host Chat Ngorsuraches invited COVER-MS researcher Farren Briggs to discuss the COVER-MS vaccine reactions results. Dr. Briggs also reviewed the development of the COVID-vaccines and how they work. We encourage you to [watch the recording](#) and see how the data you provided has been analyzed and used. Don't miss the next Chat with Chat Webinar, entitled "Telemedicine and MS: Perspectives from Patients and Health Care Providers" with guest speaker Dr. Mitch Wallin on June 8, 2022 at 4 pm EST, register [here](#).



Not already a member of iConquerMS? Please consider [joining](#) today! We always welcome questions and feedback at [info@iConquerMS.org](mailto:info@iConquerMS.org). Thanks for your help in conquering COVID-19!

May 2022 Research Spotlight

## RESEARCH OPPORTUNITIES



### Complete your REAL MS surveys!

New REAL MS surveys have landed on your iConquerMS dashboard! Please [log in](#) today and fuel MS research by completing your open surveys. The information you provide will not only accelerate MS research, but also help us tailor upcoming research opportunities for you. Knowing information about your demographics and MS history means that when the right opportunity comes along, we can reach out to YOU!

**How to accelerate MS research (and ensure we can contact you with additional research opportunities!):**

Visit your dashboard (you'll be prompted to log in).

Click on the "View and Complete My Research Surveys" button.

Complete your first open survey.

Repeat until you have no more open surveys!

Thank you for your continued participation! Your health information is important even if you think things haven't changed much in the last few months. Your data, especially your REAL MS data, has power! If you are not already a member, please consider [joining](#) iConquerMS, the only people-powered research network for MS!

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**Are you a mother with Multiple Sclerosis?**  
**If so, we would love your participation!!**

**Why:** We are Occupational Therapy students who are conducting a research study to better understand the different components of parenting among mothers with Multiple Sclerosis

**What:** 30-minute survey

**Who:** Mothers with Multiple Sclerosis age 18 years or older, with child(ren) 40 years or younger

**For more information about this study, please reach out!**

**Secure Email:** [csudh.otmothering@protonmail.com](mailto:csudh.otmothering@protonmail.com)





## **Calling all MS Caregivers! Insights needed!**

An MS caregiver or care partner is a person who provides unpaid support (physical, emotional, logistical, and social) to a person living with MS. Most of the members of iConquerMS are diagnosed with MS and may have a loved one or friend who serves as an MS caregiver. If that is true for you, [please invite your MS caregiver to share their insights with us!](#)

At iConquerMS, we're committed to infusing MS research with the perspectives and priorities of **all affected by MS**. Our iConquerMS people-powered research network now has more than 8,000 members who are driving, shaping, and fueling MS research.

**We're expanding iConquerMS to include MS caregivers as research partners.** Caregivers not only have unique insights to contribute to MS research but also have their own needs and priorities that can be addressed by research. Our goal is to improve the health, healthcare, and quality of life of MS caregivers.

As we design the expanded iConquerMS initiative, we're turning to the experts -- the MS caregivers -- to tell us what iConquerMS should include in order to best meet caregiver needs.

Help us shape the initiative by sharing this [10-minute survey](#) with your MS caregiver (or taking it yourself if you are one!). We're offering a \$10 gift code for

completed surveys from eligible caregivers. Thank you for driving, shaping and fueling MS caregiver research!

[Take the MS Caregiver Survey!](#)



**Your health data  
has power!**

### **A new topic for the Our Questions Have Power program!**

When it comes to MS symptoms and how to manage them, what questions are most important to you? What symptom-related topics do you wish researchers were studying? **Your questions are valuable** and we invite you to share them through the **Our Questions Have Power** program on the [iConquerMS](#) website.

[The Our Questions Have Power program](#) was launched in March 2021 with an initial focus on COVID-19. Questions submitted by iConquerMS members have helped shape the [COVER-MS vaccination study](#) and are being shared with the research community to guide other efforts.

We're now extending Our Questions Have Power to include a second topic: **MS symptoms and their management and treatment**. As before, you're invited to share questions on this topic that you think should be studied and to vote on questions submitted by other iConquerMS members. We'll share these questions with people affected by MS, researchers, healthcare professionals, advocates, and

funders – and, together, we’ll work to launch research studies to answer those questions.

**It’s easy to share your ideas and input in Our Questions Have Power!**

Log in to iConquerMS to start (create an account first if you don’t already have one).



Click **PROPOSE an MS Research Question** to submit a question you’d like to see studied.



Click **VOTE and COMMENT on MS Research Questions** to review, comment, and vote on questions submitted by other iConquerMS members.