

November 2021 Newsletter



November 2021 Research Spotlight

RESEARCH OPPORTUNITIES



**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 with an initial focus on COVID-19 questions. 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 into [iConquerMS](#) to start (create an account first if you don't already have one).
 - Have a research question to submit? Click **PROPOSE an MS Research Question** to submit a question you'd like to see studied.
 - Want to weigh in on other people's ideas? Click **VOTE and COMMENT on MS Research Questions** to review, comment, and vote on questions submitted by other iConquerMS members.
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Share your MS diagnosis experience

Receiving a diagnosis of MS is a life-changing experience. The support and information given during the process can vary greatly from person to person. A team of researchers from the US and Italy are studying the diagnosis experience for people with MS to learn about ways in which the process could be improved. They are also interested in learning how people with MS prefer to disclose, or not disclose, their diagnosis to others.

You are invited to help with this study by taking a survey available on iConquerMS. This study is open to all iConquerMS members who have been diagnosed with MS. We hope you will take part!

Study participants will be entered into a drawing for an Amazon Gift Card. We will be awarding twenty \$50 gift cards and forty \$25 gift cards.

Who can participate?

Anyone who has been diagnosed with MS.

What does the study involve?

The study involves completing an on-line survey on the iConquerMS web site. It will take approximately 20-25 minutes to complete.

Who is funding the study?

The study funder is the University of Vermont.

How can I take the survey?

Log into your account at www.iConquerMS.org and click the button that says, “View and Complete my Research Surveys.” You’ll see a survey named “MS Diagnosis Experiences.” Click on the survey name to get started.

If you have any questions, please email us at info@acceleratedcure.org and we’ll be happy to help. Thank you for helping us learn about and improve the diagnostic process for MS!



A New MS Aging Study

Our research partners at the Albert Einstein College of Medicine in New York City are conducting a study of aging and walking in MS.

What is the study?

The goal of this research study is to evaluate how the brain is involved in walking in older adults with and without MS. The results will provide valuable new information about how brain structure and function affects the ability to walk and influences the risk of falling. If successful, the findings may lead to possible new treatments that could improve brain control and efficiency of walking.

What is involved?

Participation begins with a telephone interview to see if the study is a good fit for you. If it's a good fit, and you agree to participate, you will have two study visits around 3 hours long at the research center at Albert Einstein College of Medicine. You will be asked to fill out some questionnaires, complete a few tests that assess cognitive functions (e.g., memory, attention), participate in some walking tests, and have one MRI.

The research team will arrange free private transportation to and from the research center for each visit. You will be paid \$100 for each visit for a total of \$200.

The research team strives to make your experience a positive one and has put in place several precautions to ensure your safety during the pandemic. The staff is vaccinated, always wear masks, and maintains appropriate distance. Study visits are conducted with only one person at a time.

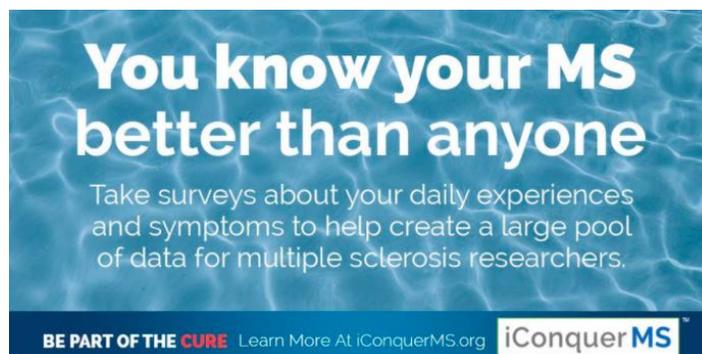
Who can participate?

The researchers are looking for people who:

- Are at least 60 years of age
- Have been diagnosed with relapsing remitting MS (RRMS) or secondary progressive MS (SPMS)
- Can walk 20 feet without assistance or with a single-point cane
- Have been on the same MS disease-modifying therapy for at least 6 months
- Meet additional study criteria

Interested in participating?

[Complete this form](#) to let the research team know of your interest. You can also call or email them at 718-430-3972 or holtzer.neuropsych@gmail.com



Complete your REAL MS surveys!

In the summer of 2016, the iConquerMS initiative launched REAL MS (Research Engagement About Life with MS), a longitudinal study of MS. Participants complete questionnaires online twice each year on a variety of subjects, including health history, diet, exercise and their experience with MS. **The next round** of REAL MS surveys is available now through the [iConquerMS portal](#). Completing these surveys is one of the simplest ways

you can accelerate MS research. The information collected will play a pivotal role in helping scientists and clinicians gain a better understanding of the health and quality of life over time for people with MS. REAL MS is just one of the many ways iConquerMS is facilitating research on topics of importance to people affected by the disease. If you are not already a member, please consider [joining](#) iConquerMS, the only people-powered research network for MS!