

June 2023 Newsletter



Can that affect my MS, too?

Many personal traits and aspects of daily living can affect your health and wellbeing. These factors are referred to as social determinants of health (SDH). A number of SDH influence the course and outcome of MS, but more research is needed to fully understand their impact. The [iConquerMS Research Inclusion Diversity and Equity \(RIDE\) Council](#) is working to make MS research fully inclusive, which will shed light on MS outcomes in people from different racial, ethnic, and social groups.

Social Determinants of Health

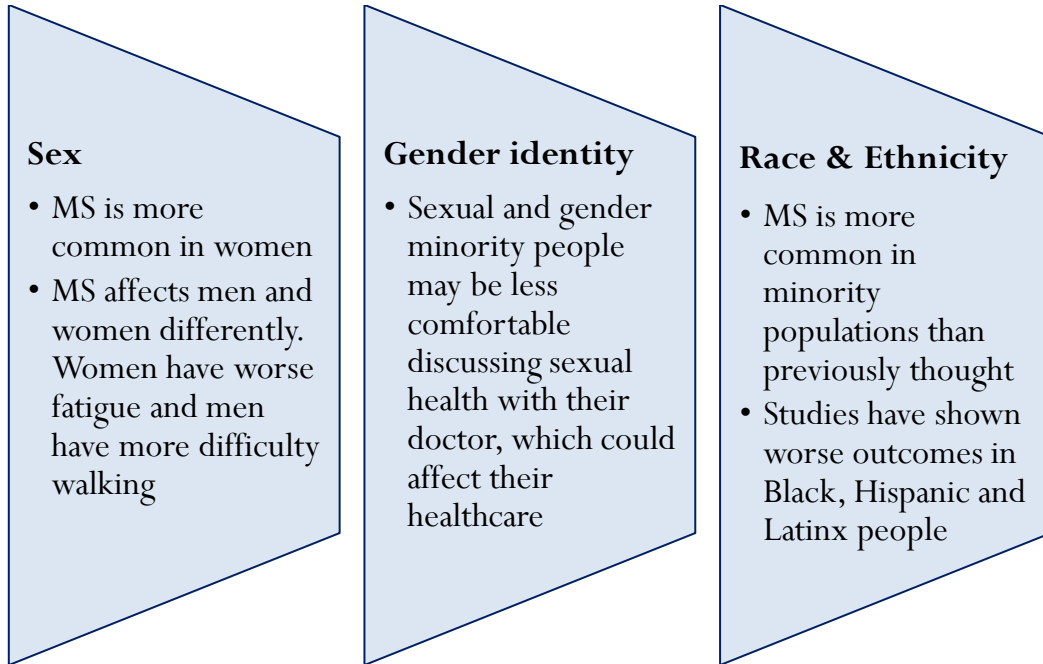


According to the [World Health Organization](#), “The SDH are the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life.”

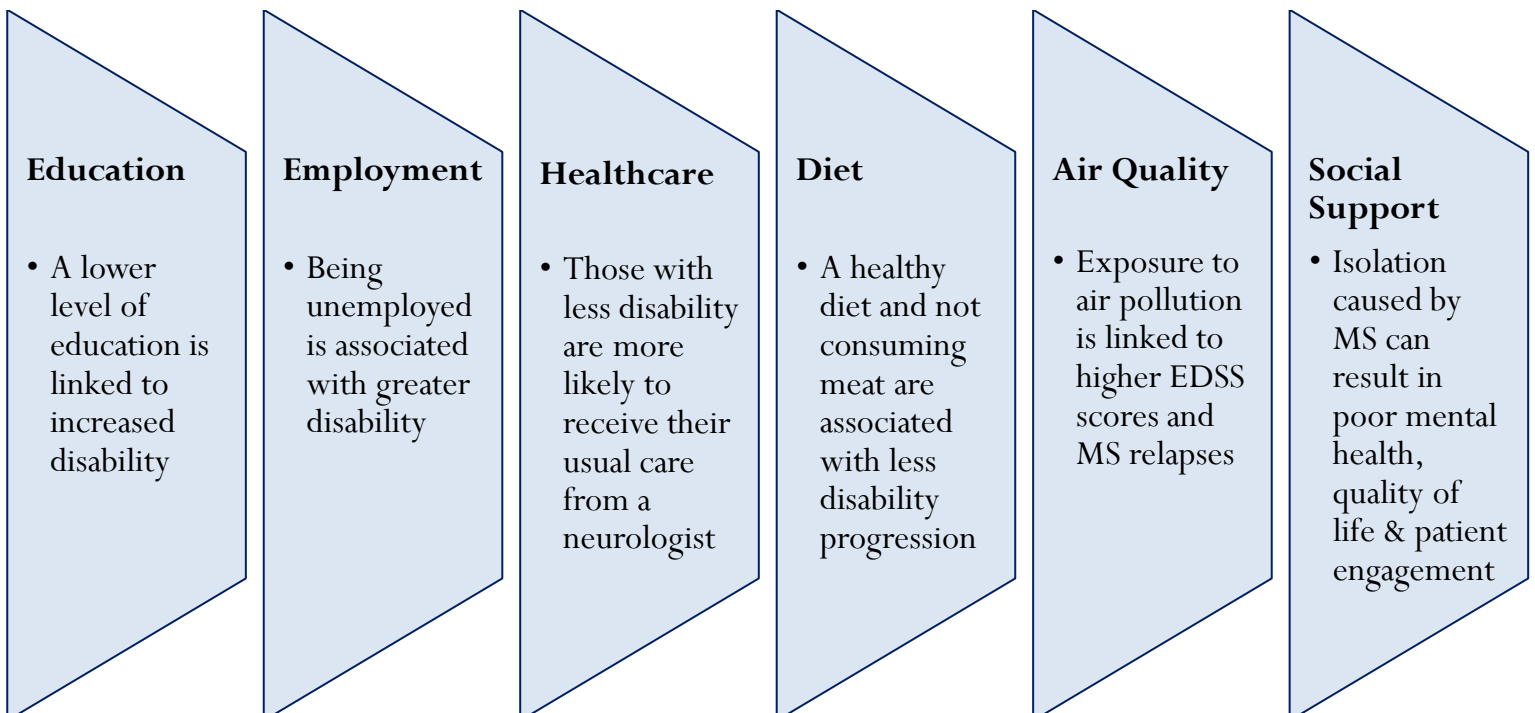
SDH include individual characteristics, such as gender, race and ethnicity. They also include external factors, like the environment, healthcare access, economic stability, education, and social support, to name a few. It’s important to note that SDH often influence each other. For example, a person’s education will determine their occupation which, in turn, can influence their economic status, healthcare, and where they live.

A [recent review](#) discusses the effect of several SDH on MS outcomes, which are summarized below:

Individual SDH that influence MS outcomes:



External SDH that influence MS outcomes:



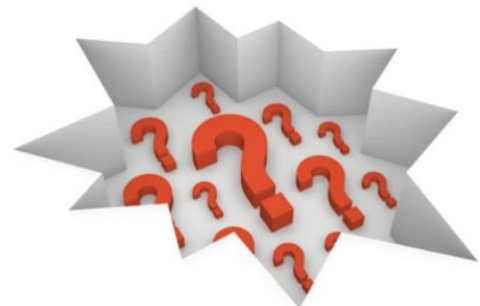
Although MS was historically thought to be most common in white people, [evidence](#) now suggests that it occurs more often in minority populations than previously thought. Research also shows that the course of the disease is different for individuals in these cohorts.



A [2004 study](#) was one of the first to characterize MS in Black Americans. Results showed Black Americans have a slightly older age at onset and a higher prevalence of visual symptoms than white Americans, with more rapid disease progression. A more recent [study](#) in people with MS identified more rapid brain and retinal atrophy in Americans from African ancestral backgrounds than Americans from European ancestral backgrounds. [Researchers](#) at UCLA compared MS mortality rates in five groups: non-Hispanic white, non-Hispanic Black, non-Hispanic Asian or Pacific Islander, non-Hispanic American Indian or Alaska Native, and Hispanic. Among individuals aged under 55 years, non-Hispanic Black Americans had the highest MS mortality rate of all these groups.

There is growing evidence that MS manifests differently in Hispanic/Latinx individuals, too. According to [investigators](#) at USC, Hispanic whites are more likely to have relapsing remitting MS with a younger age of onset and presenting symptoms of optic neuritis and transverse myelitis than non-Hispanic whites. A [2016 study](#) suggests that Hispanic/Latinx people who are diagnosed with MS before age 18 are more likely to have initial symptoms of seizures and cognitive changes. Results show those diagnosed as an adult are more likely to have severe disability, with spinal cord involvement as an initial symptom. Research looking at MS in Asian individuals is limited. Traditionally, the disease is thought to be relatively uncommon in this population. However, [investigators](#) in Spain recently concluded that the prevalence of MS in China has risen in recent years. They state the ethnic, environmental, and socioeconomic factors at play in these findings are not well understood.

Despite progress in understanding MS in minority populations, substantial gaps in our knowledge remain. Filling these gaps is limited by a [lack of diversity](#), or low enrollment of minority populations, in MS clinical trials. For example, according to a recent [editorial](#), Black participants made up only a fraction of the total enrollment in large-scale Phase 3 clinical trials for three



FDA-approved MS therapies – [Ocrevus](#), [Mayzent](#) and [Zeposia](#). This is a big issue for the MS community, given that people of color often experience more severe symptoms of the disease. These pivotal trial data are necessary to fully understand the side effects and efficacy of these treatments in this population.



The iConquerMS RIDE Council is a group of people with MS belonging to traditionally underrepresented racial, ethnic, and social groups that is working toward transforming MS research so it, and the evidence that is generated as a result, reflects all individuals – regardless of race, ethnicity, orientation, or economic status. The RIDE Council is focused on broadening participation in research by highlighting the voices and experiences of people from traditionally underrepresented communities. The Council includes dedicated sub-councils focused on specific groups, including Black/African American, Hispanic/Latinx, Asian American, rural, LGBTQ+, veteran, and disabled people. Their work brings us one step closer to ensuring that all individuals living with MS can receive the best information, outcomes, and care possible.

The RIDE Council provides key support to all stakeholders in MS research:

<p>People with MS have a group exclusively focused on ensuring their community is represented in clinical trials.</p>	<p>Researchers have a resource to help ensure they meet diversity goals and requirements in their studies.</p>	<p>Organizations have a resource to help reach and meaningfully include historically marginalized groups in their work.</p>

The RIDE Council has developed a set of pamphlets to help all people affected by MS cope with some of the most common challenges that they may face. These [resources](#) relate to a number of SDH for people with MS, including access to healthcare, social support and economic considerations.



Click on each image to access the full resource

Most neurologists use physical symptoms and diagnostic testing to diagnose MS, direct treatment, and measure outcomes. SDH have a significant impact on these parameters. A more holistic approach that considers the context of the person has the potential to further reduce the burden of living with MS. More research is needed to better understand the effect of SDH on MS outcomes, including how these factors may interact. As with all MS research, these studies should reflect the heterogeneity of the MS population to ensure that its findings apply to all. The RIDE Council is dedicated to making diversified research the norm. Assessing and addressing SDH in this way could fundamentally improve healthcare and quality of life throughout the MS community. Want to be a part of this exciting movement? If you're not already a member, please consider [joining](#) iConquerMS, the only participant-driven MS research network!



What's the best treatment for primary progressive MS?

iConquerMS empowers all people living with MS to participate in research. We are seeking participants from all parts of the country, from all backgrounds and ethnic groups, and of all ages and types of MS. With this diversity, researchers can dive deep into the workings of the disease and answer questions like what causes MS? What affects the progression of MS? What treatments work best in which people? How can we develop better treatments and eventually find a cure?



According to the National MS Society, there are four [types of MS](#):

- Clinically Isolated Syndrome
- Relapsing remitting MS (RRMS)
- Secondary progressive MS (SPMS)
- Primary progressive MS (PPMS)

Approximately 10 to 15 percent of people with MS have PPMS, where neurologic functions steadily worsen from the beginning. There are no flares in disease activity and there is no recovery, or remission. PPMS affects men and women equally. On average, symptom onset occurs between ages 35 to 39 and the rate of disease progression varies.

There are more than a dozen FDA-approved [disease modifying therapies](#) for the treatment of RRMS. These drugs typically work by decreasing inflammation and reducing the number of relapses an individual may have. They are not usually effective in treating PPMS because this form of the disease does not involve significant inflammation. [Ocrevus](#) (ocrelizumab) is the only FDA-approved treatment for PPMS. It is administered by infusion (600 mg) every 6 months.



A distinct type of nerve damage occurs in PPMS. It involves much less inflammation than RRMS. Individuals with PPMS tend to have more lesions in the spinal cord and the lesions tend to contain fewer inflammatory cells.

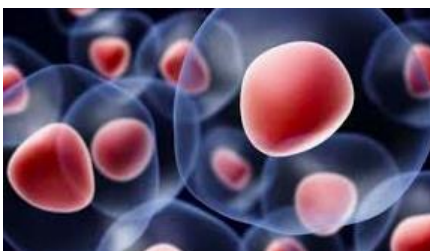
Research to better understand and treat progressive MS continues with additional novel treatments in the pipeline.

PPMS medications in [Phase 3 clinical studies](#):

Medication	How is it taken?	How does it work?	Relevant Research
Ocrevus	Infusion	Targets lymphocytes	Research is underway looking at the safety and effectiveness of a higher dose of Ocrevus in adults with PPMS.
Masitinib	Oral	Tyrosine kinase inhibitor	The MAXIMS study is evaluating whether or not Masitinib could be a potential treatment for progressive forms of MS.
Tolebrutinib	Oral	Tyrosine kinase inhibitor	Tolebrutinib has shown promise for the treatment of RRMS in Phase II trials . The PERSEUS study is determining its effectiveness in PPMS.
Fenebrutinib	Oral	Tyrosine kinase inhibitor	The FENTrepid study is assessing the safety and effectiveness of Fenebrutinib, compared with Ocrevus, in adults with PPMS.

PPMS medications that are in or have undergone [Phase 2 clinical testing](#):

Medication	How is it taken?	How does it work?	Relevant Research
Mavenclad	Oral	Targets lymphocytes	The ChariotMS study is evaluating if Mavenclad can slow progression of upper limb disability in people with advanced MS.
Ibudilast	Oral	Phosphodiesterase inhibitor	Research shows Ibudilast slows the rate of brain atrophy in progressive MS, but it has significant side effects.

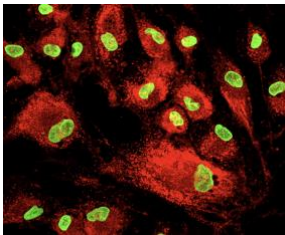
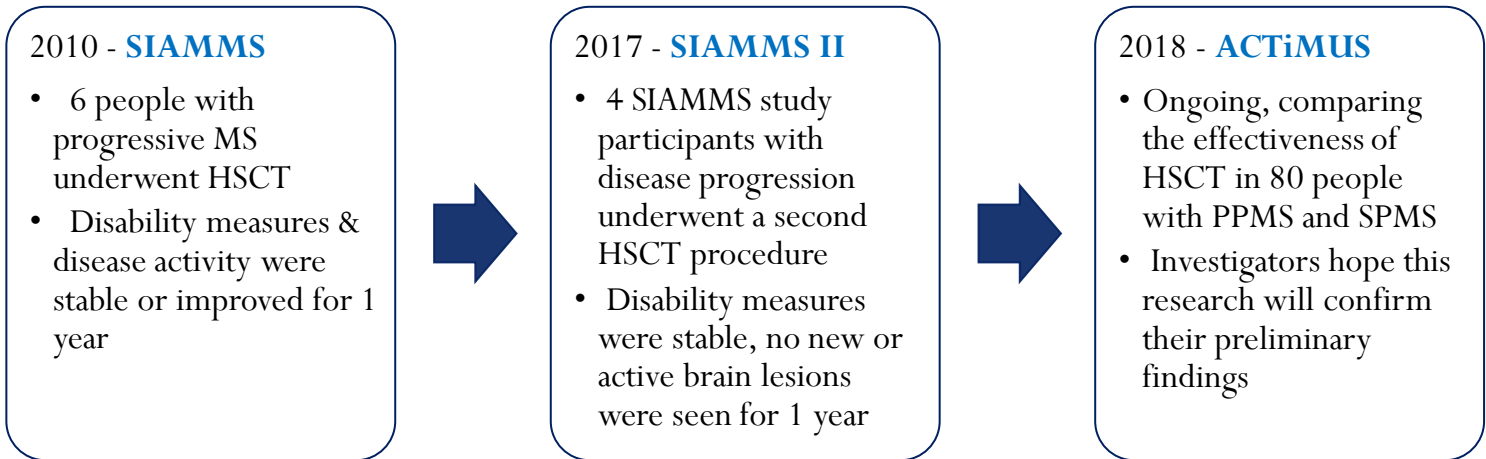


[Stem cell therapy](#) has shown substantial benefit in people with RRMS. It's important to note that more research is needed before it becomes a widely used treatment for PPMS. The goal of stem cell therapy is to promote the immune system to repair damage and reduce

inflammation in the brain and spinal cord. In a procedure known as [hematopoietic stem cell transplantation](#) (HSCT), stem cells are collected from a person's own tissues, like bone marrow or blood, and then reintroduced after their immune system has been suppressed.

What research has been done on HSCT as a treatment for PPMS?

Investigators in the United Kingdom have conducted a series of studies into this subject:



[Mesenchymal stem cells](#) (MSCs) are adult stem cells isolated from different sources, such as bone marrow, fat tissue, umbilical cord or blood, that can differentiate into other types of cells.

What research has been done on MSCs as a treatment for PPMS?

Researchers at the Tisch Multiple Sclerosis Research Center of New York have conducted the following studies:

2016 - Pilot study

- 6 participants with progressive MS underwent IT administration of MSCs (injection into the spinal cord)
- 4 out of 6 participants showed clinical improvement



2021 - Phase I study

- 20 participants with PPMS had 3 IT MSC injections, 3 months apart
- Most showed less or stable disability over 2 years
- Those with more advanced disease and greater disability did not show benefit



Complementary and alternative therapies (CAM) are considered nonconventional treatments (for example, acupuncture and dietary supplements). Many people incorporate some type of CAM as part of their MS management, even though very limited research has

been done to evaluate their safety and effectiveness in MS. Anyone considering this option should talk to their doctor first and continue to adhere to any prescribed treatments he or she recommends.

What research has been done on CAM for progressive MS?

CAM in general –

- A [2010 study](#) showed the most promising CAM for progressive MS include a low-fat diet, omega-3 fatty acids, lipoic acid and vitamin D supplementation.

Research into CAM for progressive MS (continued...)

Biotin –

- A [2016 study](#) showed high-dose biotin treatment is well tolerated and led to reversal of MS-related disability in a subset (13%) of participants with progressive MS.
- A [2020 study](#) suggests that high-dose biotin does not significantly improve disability or walking speed in people with progressive MS and warns that this treatment interferes with laboratory testing, which may have harmful health consequences.

Lipoic Acid –

- A [2017 study](#) found lipoic acid treatment led to significantly less brain atrophy in participants with SPMS over a 2-year period and it was well tolerated.
- The [LAPMS trial](#) is evaluating whether lipoic acid can preserve mobility and protect the brain in progressive forms of MS

People living with PPMS face the possibility of gradually losing function with each passing day, potentially losing the ability to do the things they enjoy. Accelerating research into finding effective treatments for this and other types of the disease is of prime importance.

iConquerMS is leading the charge in a new generation of MS research, where people living with the disease are at its center, contributing their data and ideas as a driving force for future studies. If you haven't already, please consider [joining](#) iConquerMS, the only participant-powered MS research network, today! Together, we can advance MS research more rapidly toward better treatments and eventually cures!



**BE PART
OF THE
CURE**

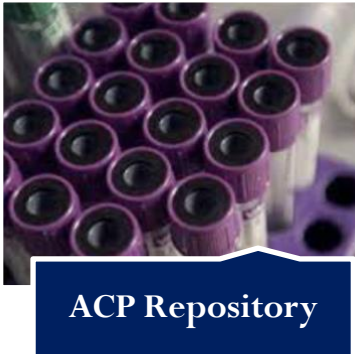
Join the online
effort to advance
MS research.

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June 2023 Donor's Corner

How do your [donations](#) accelerate research for a cure and improve the lives of people affected by MS?

Your generosity supports ACP's initiatives to accelerate MS research for quicker diagnosis, more effective treatments, and a cure for all living with the disease.



If you or a loved one have been diagnosed with MS, you know that this process can be tortuous and determining the best treatment plan isn't always easy.

This month, we're highlighting how your generosity enables [iConquerMS](#) to bring together **all** people affected by MS to understand the disease and search for solutions.



iConquerMS is leading the charge in a new generation of MS research, where people living with the disease are at its center, contributing their data and ideas as a driving force for future studies. We are seeking participants from all parts of the world, from all backgrounds and ethnic groups, and of all ages and types of MS. With this diversity, researchers can dive deep into the workings of the disease and answer questions like:

- What causes MS?
- What affects the progression of MS?
- What treatments work best in which people?

[Join](#) our team and consider making a [donation](#) today! Together, we can advance MS research more rapidly toward better treatments and eventually cures!



June 2023 iConquerMS Spotlight

The MS Diagnosis Experience To Tell or Not to Tell? That is the question.

Receiving an MS diagnosis can be stressful and some people choose to keep their diagnosis to themselves. A [recent study](#), hosted by the iConquerMS network, found that a number of factors make this decision more likely.



In late 2021, 428 iConquerMS members were surveyed about their MS diagnosis experience, communication with their healthcare providers, and whether they subsequently shared their diagnosis of MS.



Results show that approximately half of all individuals with MS conceal their diagnosis from others because they fear disclosure would have negative consequences in both their personal and professional lives.

What factors affect the decision to keep an MS diagnosis private, or to be transparent about it?

Privacy

Younger people are more likely to keep their MS diagnosis private.

Higher education was associated with concealment.

The recently diagnosed (with less visible symptoms) tend toward secrecy.

Transparency

A positive diagnosis experience makes concealment less likely.

Being given sufficient time during the diagnostic process is key.

Discussing the fear of disclosure with a healthcare provider helps.

This information suggests that having a positive diagnosis experience and openly discussing and addressing the issue of disclosing an MS diagnosis with a healthcare provider can help reduce the negative effects of keeping it a secret. It's important to keep talking about this and seek support if any concerns about revealing the diagnosis come up later on.



More research is needed to fully understand the impact of nondisclosure on the quality of life of those living with MS. iConquerMS is poised and ready to facilitate research efforts like this, which significantly impact the MS community. If you're not already a member, please consider [joining](#) today!

June 2023 Research Spotlight

RESEARCH OPPORTUNITIES

Research opportunity information may be provided on behalf of an external organization. Please refer to the contact information within each listing to identify the contact for questions or comments.



Table of Contents

Research Opportunities

Page 1

MS Caregiver Survey

Page 2

TEAAMS Exercise Study

Page 3

University of Iowa Diet Study

Page 5

Our Questions Have Power

Calling All MS Caregivers!

ACP is working with a small group of MS caregivers and MS professionals (Jon Strum of RealTalk MS, Rosalind Kalb of CanDo MS, and Deborah Miller of the Cleveland Clinic) to develop a “Caregiver Protocol.” The Protocol will be an online compilation of resources to support MS caregivers at all stages of the caregiver journey. We’ve developed a [short survey](#) (5-10 minutes, we promise!) to gather the perspectives of MS caregivers so that their insights can help shape the Protocol. Your input is valuable and much appreciated! Thank you!



RESEARCH OPPORTUNITY

University of Illinois - Chicago

This study involves the remote-delivery of 16-week exercise training program for African-Americans with Multiple Sclerosis (MS)

Benefits

- Contribute to ongoing research on African-Americans with multiple sclerosis (MS)
- Learn about methods of improving your health and well-being

Eligibility

- Diagnosis of MS
- Self-identify as African American or Black
- Living in the Southeastern United States
- 18-64 years of age
- Internet and email access



For more information,
contact Edson Flores

(833) 727-1887

enrl@uic.edu

Keyword: TEAAMS

<https://projectteams.ahs.uic.edu>



You are invited to participate in a research study comparing the effects of three diets – the modified Paleolithic diet (elimination of gluten, dairy, and eggs), a Time Restricted Olive Oil-based Ketogenic diet, or your usual diet with information about the USDA Dietary Guidelines for Americans. Participants in the usual diet group will be encouraged but not required to follow the

Dietary Guidelines for Americans diet. Quality of life, fatigue, mood, and disease activity will be assessed by online surveys, study participant tasks, & brain imaging. The study will be held at the University of Iowa Hospitals & Clinics over two years. It will consist of three visits to Iowa City, month 0, month 3, & month 24. Each visit can last approximately three and up to six hours.

What you will be asked to do at home while on your assigned study diet

- Follow one of the three study diets randomly assigned to you for 24 months
- Report changes in health and medications
- Eat more non-starchy vegetables
- Eat more home-cooked meals
- Take recommended dietary supplements
- Complete daily food logs (three questions) on a smart phone
- If you are assigned to the ketogenic diet, you must take a blood ketone measurement daily for the first month and then twice a week for the rest of the study
- Complete online surveys
- Watch videos, review study diet guides and meet via Zoom to learn your assigned study diet
- Attend optional online support groups

What you will be asked to do at each of three visits to UIHC

- Complete fasting blood draws
- Complete physical motor skills, cognitive assessment and visual function tasks
- Receive a non-contrast MRI brain scan at first and final end of study UIHC visit (Month 0 and 24)

Requirements to participate

- Diagnosis of relapsing remitting multiple sclerosis (RRMS)
- 18-70 years old
- Able to walk 25 feet without support or unilateral support
- Willingness to adopt any of the three study diets, including the control diet
- Willingness to share medical records for the two years of the study
- Do not have heart disease, liver disease, kidney disease, or type 1 diabetes
- Do not have serious psychiatric disease that would make adopting a study diet more difficult
- Are not taking insulin or coumadin
- Have a smart phone, tablet or iPad to download a free app
- Have access to high-speed internet and a computer or smart phone to participate in video conferences via Zoom and complete online patient surveys
- Commitment to completing surveys for two years and attend the of end of study visit

COMMON QUESTIONS

Do I need to live within a specific mile radius of Iowa City?

No, however, if travel funds are needed, we may be able help. We can offer a travel stipend to support some travel expenses to and from Iowa City. Please speak with us about your needs. We also offer stipends to participants for attending the site visits and for completing the required online surveys.

Can I pick the diet I want to follow?

We ask that you follow the diet assigned to you. If following your assigned diet becomes difficult contact the study team for assistance.

Can I be in the study if I am in another MS-related study?

If you are in an interventional study investigating drugs, exercise, or other wellness behaviors you cannot be in this study. If you are in an observation-only study, you can still be in this study if you are willing to follow any of the three diets.

If you're interested in taking our screening survey, please visit the link below or scan the QR code with your phone:

→ <https://redcap.icts.uiowa.edu/redcap/surveys/?s=JX73EYRJNPF9MHRR>



If you have questions, please contact us at → MSDietStudy@healthcare.uiowa.edu

→ wahls.lab.uiowa.edu/join-study



Changing Medicine.
Changing Lives.®



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.