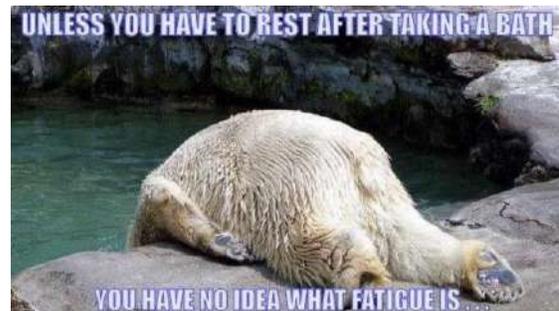


October 2023 Newsletter



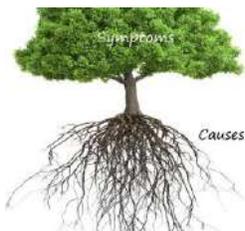
Beyond Tired – Coping with MS Fatigue

If you're a member of iConquerMS, you know that we ask you questions about your MS symptoms. According to the National MS Society, 80% of people with MS experience fatigue, and over half rank it as one of their most troubling symptoms.



Nearly everyone feels overtired or overworked from time to time, but this is usually solved by a good night's sleep. Fatigue is an unrelenting exhaustion that develops over time, is more intense, lasts longer and isn't relieved by rest.

Fatigue can be either physical or cognitive, or both. Physical fatigue may affect an individual's energy and motivation. For example, one's limbs may feel heavy and hard to use. Cognitive fatigue, on the other hand, affects concentration. Individuals with cognitive fatigue may have difficulty following a conversation or thinking of words or numbers.



In some cases, fatigue is "secondary" to an underlying cause and may be effectively addressed by treating the source.

Secondary Causes of MS Fatigue



Depression

- [Research](#) shows when depression and fatigue occur together, fatigue may be effectively addressed by treating the underlying depression.



Sleep Disorders

- The [prevalence](#) of sleep disorders in people with MS is high.
- Exhaustion from a lack of sleep is a contributing, if not a causative factor in MS fatigue.



MS Medications

- Fatigue is a side effect of some disease modifying therapies.
- Drugs taken for MS symptoms can also contribute to fatigue.



Other Medical Conditions

- Sometimes, people with MS have other medical conditions, such as infections, anemia, or thyroid conditions, which can also increase fatigue.

Beneath these secondary causes is “primary” MS fatigue, called [lassitude](#), the cause of which is unknown. Lassitude has a number of specific characteristics that help distinguish it from secondary MS fatigue.



Lassitude symptoms

- Occurs on a daily basis
- Is more severe than secondary MS fatigue
- Is more likely to interfere with daily activities
- Often occurs early in the morning, even after a restful night's sleep
- Comes on suddenly and worsens as the day progresses
- Is aggravated by heat and humidity

No matter what form of fatigue an individual with MS may experience, this overwhelming tiredness can affect anyone with MS, regardless of physical disability, and occur at any time in the course of the disease. People with MS may also find that fatigue worsens their other MS symptoms.

Researchers are working to figure out the exact cause of MS-related fatigue. There is evidence that the following body systems could be involved:



Immune System



- **Cytokines** are chemical messengers that are secreted by cells in the immune system.
- **Researchers** in Germany found cytokine levels are significantly higher in people with MS that have fatigue.
- This suggests that fatigue is at least partially mediated through activation of cytokines.

Endocrine System



- **Dehydroepiandrosterone (DHEA)** is a hormone that your body naturally produces in the adrenal gland.
- **Researchers** in Spain found that levels of DHEA are lower in people with MS with sustained fatigue.
- This suggests that the endocrine system may play a role.

Central Nervous System



- Other studies suggest that MS fatigue stems from damage to the central nervous system caused by demyelination.
- Swiss **researchers** suggest that a reduced transmission of electrical signals in the brain may play a role.
- Canadian **researchers** suggest that nerve loss is a contributing factor.

How is MS fatigue treated?



In some cases, drugs may be used to treat fatigue. However, medication is not a solution to fatigue on its own. Because different factors can cause or add to MS-related fatigue (like depression or sleep disorders), anti-fatigue medications should be used in conjunction with treatment for these factors (when applicable). It's also important for people with MS to see their physician regularly to ensure their disease is under the best control possible.

Anti-Fatigue Medications

Modafinil (Provigil) is used to treat fatigue and sleepiness. **Studies** suggest that low dose modafinil significantly improves both, and is well tolerated in people with MS.

Armodafinil (Nuvigil) is a medication that is similar to modafinil and is also prescribed for the treatment of MS fatigue.

Amantadine (Symmetrel) is an antiviral medication that has been used to treat MS fatigue since the 1980s, although its **benefit** in this regard is not well documented.

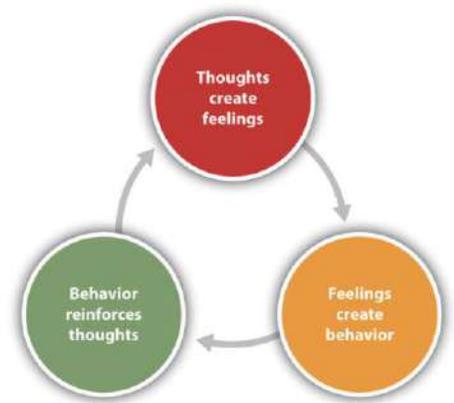
Anti-Fatigue Medications continued...

Methylphenidate (Ritalin) is a central nervous system that can be helpful in reducing MS fatigue. [Studies](#) are underway to confirm this benefit.

Dextroamphetamine (Dexedrine) is also a stimulant medication. Its effects on MS fatigue are similar to those of methylphenidate.

[Research](#) suggests that **aspirin** may lessen fatigue in people with MS. More study is needed to understand the benefit and risk of aspirin treatment for people with MS.

There is [evidence](#) that Cognitive Behavioral Therapy (CBT) is helpful in relieving MS fatigue. CBT is a common form of psychotherapy where people learn to change their unhelpful thoughts and actions. The core premise of CBT is that thoughts, feelings and actions are connected. By working on negative thoughts and behaviors, people can feel better and handle challenges more effectively.



A number of **alternative therapies** may provide some benefit for MS-related fatigue.

Caffeine



Some people with MS find caffeine is helpful in managing fatigue. It is an irritant to the bladder, however, and can increase urgency and frequency.

Acetyl-L-carnitine



Acetyl-L-carnitine is a dietary supplement that appears to reduce MS-related fatigue, however research to support this benefit is mixed.

Herbs



Herbal remedies for fatigue include ginkgo biloba, valerian, St. John's wort and ginseng. Many have side effects to consider before use.

Tai Chi



Some turn to Tai chi for relief of their MS fatigue. [Studies](#) don't support this benefit, but show it does improve balance and quality of life.

Strategies to conserve energy are often helpful in managing fatigue. An analogy can be made for people with MS between bank accounts and energy levels. Both benefit from the same rule of thumb – less money, or energy, used now means more will be available later on.



Energy Conservation Strategies

- Ration your energy throughout the day
- Plan your activities
- Schedule breaks to rest and recharge
- If a task is too large, divide it into smaller parts

Be efficient while performing household duties.

- Arrange supplies in advance to minimize the amount of time spent standing
- Have food delivered, if possible
- If you need to shop, make a list and go to a store that you're familiar with
- Select menus in advance with easy recipes
- Prepare double portions of a meal and freeze leftovers for another day

Avoid triggers that may cause fatigue.

- Avoid extremes in heat
- Stay in air-conditioning, if possible
- If not, cool down with a fan or spray bottle



MSAA's [Cooling Distribution Program](#) offers cooling vests, smaller products to wear under clothing and other accessories to help people with MS keep cool.

Healthy living can also make MS fatigue more manageable.

	Eat a well balanced, healthy diet
	Get regular, moderate exercise <ul style="list-style-type: none">• Avoid the hotter periods of the day• Try exercising in water
	Manage stress <ul style="list-style-type: none">• Adjust expectations and limit daily to-do lists• Try relaxation techniques
	Support groups can be a source of comfort and camaraderie

Managing fatigue in MS is complex and requires teamwork among people with MS, their family, caregivers and healthcare providers. iConquerMS brings together all of these individuals, in collaboration with researchers, to understand MS and search for solutions. Did you know that network members will be instrumental in testing the effectiveness of a new CBT treatment for MS fatigue? Click [here](#) to learn more! Would you like to be a part of this and other exciting research opportunities for people with MS? If you haven't already, please consider [joining](#) iConquerMS today!



3 Reasons to Join iConquerMS

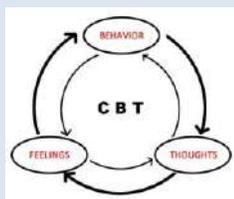
- TRACK YOUR HEALTH WITH NEW TOOLS**
You will have access to a new Real MS™ diary feature and be able to upload and store your electronic health records to track your health and medical history.
- CONTRIBUTE TO MS RESEARCH**
Your voice matters. Provide ideas for topics and questions to move research in directions that are important to you. iConquerMS™ makes it easy to participate.
- STAY IN THE KNOW**
You will receive updates on MS, important news, research findings, and opportunities to participate in research.

Learn More at iConquerMS.org

CAFE-MS (Confirmatory Trial for Alleviating Fatigue with Elevida in Multiple Sclerosis (MS))

The iConquerMS community has contributed to many research studies on a wide variety of relevant topics for people with MS, including [lifestyle and health outcomes](#), [complementary and alternative medicine](#), and [COVID-19 vaccines](#). Network members will soon have the opportunity to help evaluate the effectiveness of a new, non-drug treatment for MS fatigue.

There is [evidence](#) that Cognitive Behavioral Therapy is helpful in relieving MS fatigue. CBT is a form of psychotherapy where people learn to change unhelpful thoughts and actions. The core premise of CBT is that thoughts, feelings and actions are connected. By working on negative thoughts and behaviors, people can feel better and handle challenges more effectively.



[ELEVIDA](#) is a software program, produced by [GAIA AG](#), that is used to treat MS fatigue abroad. It serves as a guided therapy session that changes according to individual responses, using concepts from CBT and [mindfulness](#). Users can work through it, answering multiple choice questions at their own pace and the software adapts based on their answers to fit their needs. The program is typically used once or twice per week as a supplement to usual disease modifying therapy.

In ELEVIDA, information is shared using simulated dialogues. After a quick 5-minute registration, users can begin the first of eight interactive “chats.” These conversations consist of a series of interactive web pages that are tailored to each user based on their traits and answers using predetermined algorithms. All modules are comprised of an introduction and a summary and include homework tasks. Each one takes approximately 30 to 60 minutes to complete.



ELEVIDA Modules

Introduction	Understanding CBT	Balancing Activity and Rest	Improving Sleep Quality
Attention and Interpretation Patterns	Changing Thoughts to Cope with Fatigue	Reducing Stress with Relaxation Techniques	Seeking Social Support & Preparing for the Future



ELEVIDA establishes an individualized fatigue model for each user in the first module that can be adjusted as needed. The software includes instructions for using the program effectively and sections devoted to commonly asked questions, management of usernames and passwords, references (with research articles from the program) and technical support. It offers the option of receiving daily text messages, which reinforce concepts discussed in the “chats,” encourage user participation and serve as reminders of the program’s availability.

In 2018, [researchers](#) in Germany evaluated ELEVIDA’s effectiveness at reducing fatigue in people with MS. They divided 275 participants with MS and fatigue into two groups. One group was treated with ELEVIDA in addition to standard care for 12 weeks, while the other received regular care only. The ELEVIDA group experienced less fatigue than the control group. Data showed using ELEVIDA also made their quality of life better, they felt less anxious and they could do daily tasks more easily. These improvements lasted for 6 months, suggesting they learned skills to manage fatigue even after the program ended. In 2021, this study served as the basis for ELEVIDA’s approval in Germany to treat MS-related fatigue.



ACP recently received a Clinical Trial Award from the [Department of Defense Office of the Congressionally Directed Medical Research Programs](#) (CDMRP) to conduct the CAFE-MS (Confirmatory Trial for Alleviating Fatigue with Elevida in Multiple Sclerosis (MS)) clinical trial. This project is inspired by the positive results seen in the German study. Stay tuned for the press release in the near future!

ELEVIDA is the only CBT for MS-related fatigue to be approved and reimbursed anywhere in world.



What are the main goals of CAFE-MS?

Aim 1

- Determine if the English version of ELEVIDA effectively reduces fatigue in a wide range of people with MS in the US, in real-world conditions

Aim 2

- Establish ELEVIDA's effectiveness in specific subgroups of people with MS who are often not well-represented in clinical trials

Aim 3

- Assess how people with MS perceive ELEVIDA and whether they find it acceptable

CAFE-MS participants will be recruited from the [iConquerMS network](#) and the [Veterans Health Administration MS Centers of Excellence](#) (VA). This approach will help to ensure the participation of less represented groups in the study, including those with diverse backgrounds, living in rural areas and having disabilities. Our [preliminary survey](#) is now available for those who would like to provide input on the study design. Recruitment will begin in March 2024.

The MS population at the VA differs from the broader MS population in the US. This group includes 47.5% White men, 20.7% White women, 13.4% Black men, 11% Black women, and 7.5% from other racial and ethnic backgrounds.

What are the inclusion criteria for CAFE-MS?

Participants must:

- Have a neurologist-confirmed diagnosis of MS (all MS subtypes)
- Be 22-75 years of age
- Be able to use a computer or tablet with internet access
- Reside in the United States

Participants will be randomly assigned to receive treatment via ELEVIDA, other online educational materials, or standard of care only.



A Steering Committee with diverse membership will be established to oversee all aspects of this project. It will include people affected by MS, healthcare providers, researchers and MS clinical trial experts. As we do with all iConquerMS research projects, we are currently [surveying](#) the iConquerMS community to gather their insights on the study in advance of it launching.

Digital tools like the ELEVIDA program can be expanded more easily than in-person clinic treatments making them promising for improving healthcare, especially for those who can't easily travel to a doctor's appointment due to distance or other reasons. iConquerMS will play a pivotal role evaluating ELEVIDA's effectiveness and suitability across diverse groups of people with MS and in different settings. This clinical trial, which will be conducted with the goal of gaining FDA approval, aims to significantly advance the field by providing a much-needed, effective treatment for MS-related fatigue. If results show that ELEVIDA works for different MS groups, is accepted by fatigued individuals with MS, and is better than the current standard, it could be FDA approved and covered by insurance in the United States. Having an approved and reimbursed therapy for MS-related fatigue would be a significant breakthrough for everyone affected by MS, as well as their healthcare providers. Stay tuned!

Want to steer the direction of MS research and get more involved in projects like this, that significantly impact people affected by MS? If you haven't already, please consider [joining](#) iConquerMS today!

iConquerMS
empowers people
living with MS

Unlike other data-gathering programs, iConquerMS is governed and driven by **people living with MS.**

Participate at iConquerMS.org

iConquerMS
BE PART OF THE CURE

October 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.



ACP Repository



iConquerMS



Inclusive Engagement
in MS Research

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



The iConquerMS community has contributed to many research studies on a wide variety of topics, including [complementary and alternative medicine](#), [diet and wellness practices](#), [COVID-19](#) and related [vaccines](#) (to name a few).

iConquerMS will soon play a crucial role in a clinical trial looking at the effectiveness and suitability of a new, non-drug treatment for MS fatigue. If successful, [ELEVIDA](#) could potentially receive approval and insurance coverage in the US, marking a significant breakthrough for those affected by MS and their healthcare providers. Stay tuned for updates!



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

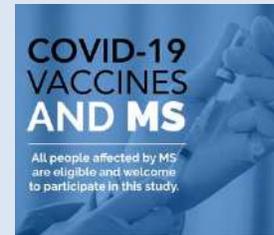


October 2023 iConquerMS Spotlight

How do COVID-19 vaccines affect people with MS?

The [iConquerMS](#) community has contributed to many research studies on a wide variety of topics, including COVID-19 vaccines and how they work in people affected by MS.

The [COVER-MS study](#) shows the frequency of vaccination reactions in people with MS is similar to that reported in the COVID-19 vaccine clinical trials.



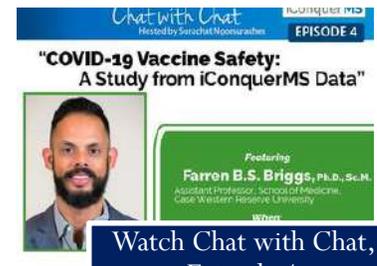
Want to learn more about what we've learned from COVER-MS so far?



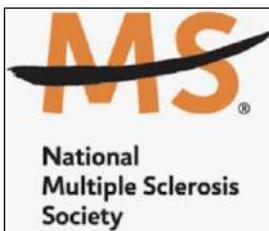
Visit the [COVER-MS Data Dashboard](#)



See an overview of [COVER-MS results](#)



Watch [Chat with Chat, Episode 4](#)



Through a partnership with Quest Diagnostics and the National MS Society, a [COVER-MS sub-study](#) is looking at the effectiveness of COVID-19 vaccines at preventing the virus in people with MS. As part of this effort, 300 COVER-MS participants will donate blood every 6 months for the next 2 years. These samples will be analyzed to determine how MS drugs and other factors affect the immune response (antibody levels) to COVID-19. We are currently inviting participants to return for a third blood draw and have been able to provide them with antibody results from rounds one and two. Analysis of these data is underway, stay tuned for the results!

iConquerMS brings together people with MS, their care partners, researchers and others to understand MS and search for solutions. If you haven't already, please consider [joining](#) today!



iConquerMS™

Who Can Join and Participate in iConquerMS?

Our goal is to have 20,000 people living with MS from **all backgrounds, ages, and stages** of the disease.

Anyone who cares about MS can join!
Even if you haven't been diagnosed with MS, your participation is still valuable.

 Learn about who else is welcome to join & participate at iConquerMS.org

October 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

BIPAMS Cognitive Health Study

Page 3

METS for MS Exercise Study

Page 4

TEAAMS Exercise Study

Page 5

University of Iowa Diet Study

Page 7

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](#) 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!

STUDY2022-0084-MOD006
Effective: 8/11/2023
UIC Office for the Protection of Research Subjects

Research Opportunity

Researchers at the University of Illinois Chicago (UIC)
Invite You to Participate in a Voluntary Research Study

This is a nationwide, remote study that is examining the effects of two Internet-delivered programs for improving cognitive health among people with MS.

All participants in this study will complete online questionnaires, virtual cognitive and mobility testing, and wear an accelerometer. An accelerometer is a small device that measures physical activity by measuring steps/day.

The entire study can be conducted at home as no in-person visits are needed. Also, currently physically inactive refers to those who are not doing enough physical activity.

Participation in the study will last 12 months and participants will receive \$50 in compensation via gift cards for completing the 3 measures for a total of \$150.

Initial eligibility

- Diagnosis of multiple sclerosis (MS)
- 18 years of age or older
- Internet and email access
- Currently physically inactive
- Able to walk without assistance

For More Information:
Contact the Project Coordinator

Key Words: BIPAMS-Cognition

Phone: (833) 329-1441

Email: bipamscognition@uic.edu

Website:

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



Behavioral Intervention for Physical Activity
in Multiple Sclerosis - Cognition

RESEARCH OPPORTUNITY

University of Illinois at Chicago



Exercise Training for Managing Major Depressive Disorder in Multiple Sclerosis

METS for MS

The **Mood and Exercise Training Study for Multiple Sclerosis (METS for MS)** is looking at the use of exercise as a non-medicinal treatment for persons with MS who also have depression. METS for MS involves the remote delivery of a 4-month exercise training program with a 4-month follow-up period.

The study involves 3 University of Illinois Chicago site visits over the course of 8 months. Site visit testing includes mental health screeners, muscle strength testing, aerobic testing, walking speed testing, and cognition testing.

Coaching and all equipment needed for exercises will be provided by the study. Participants will be paid \$100 for each site visit completed.

Eligibility:

- Multiple sclerosis diagnosis
- Major depressive disorder
- Internet and e-mail access
- Willingness to complete training
- Physically inactive
- Able to walk
- 18-64 years of age
- English as a primary language
- Live within 100 miles of Chicago

Benefits of Participating:

- Improve your health and wellness through exercise training
- Contribute to ongoing research on persons with MS



Department of Kinesiology and Nutrition

FOR MORE INFORMATION

**CONTACT THE EXERCISE NEUROSCIENCE RESEARCH LAB:
1(833)413-0280
METSFORMS@UIC.EDU**



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

Contact us for more information

(833) 727-1887
enrl@uic.edu
Keyword: TEAAMS



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.