

# August 2023 Newsletter



## ACP collaborates with caregivers!

Traditionally, caregivers have generally played a peripheral role in research. However, their perspective is vital in every step of the research process. Increasing the number and impact of caregiver-focused studies are important goals, too. ACP has a number of ongoing activities aimed at relieving [caregiver burden](#) and increasing the voice of this important population in research, including both MS-focused and caregiver-focused studies.



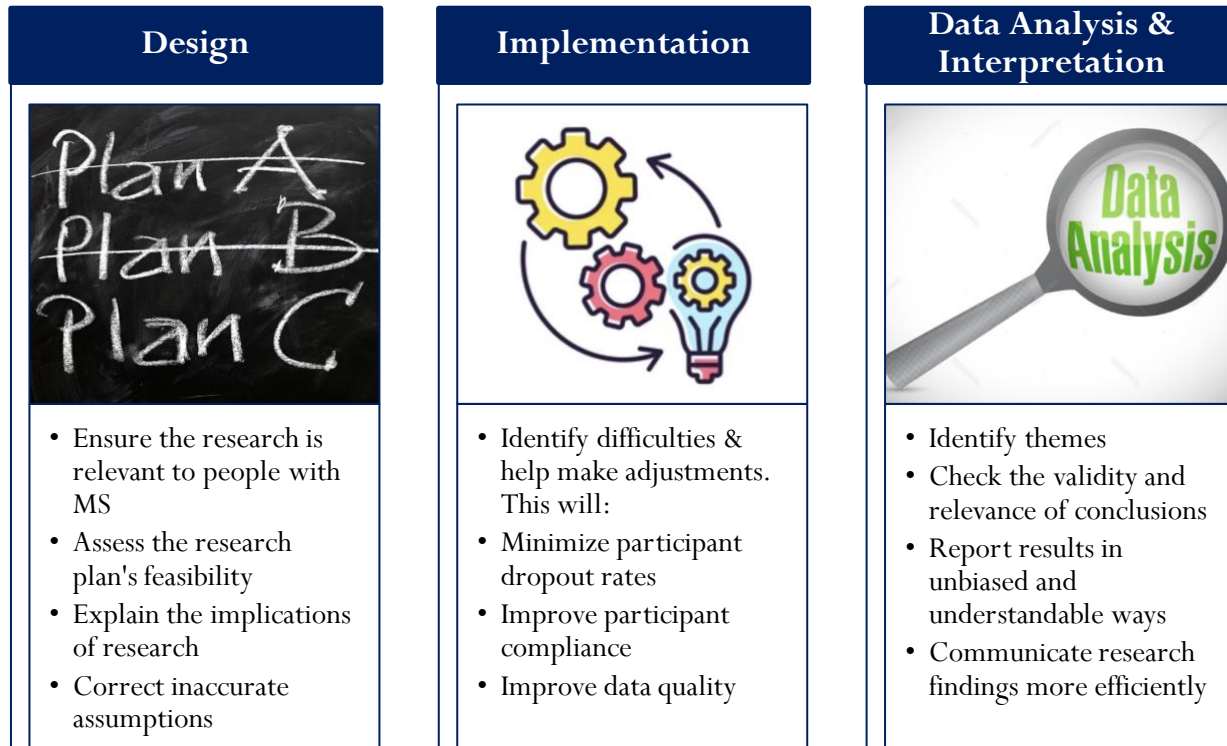
MS caregivers live the experience of the disease. They are the closest and most constant observers of people with MS. Their knowledge of side effects, as well as physical or cognitive changes, and how these affect functioning and quality of life is second to none.

**Why is caregiver-focused research so important?** Caring for a loved one with MS is a 24/7 job that can span decades. Those providing support are often so focused on their partner's needs they may not have time, or think to take care of their own. It's important to investigate caregiver health and burden, as well as coping mechanisms and strategies. Learning more about these important topics will help sustain a vital relationship that is the backbone of many families.

**"It's non-stop, it's unrelenting and we have to respond and adapt and do the best we can."**

*Care Partner Advisory Panel Participant*

## How can a caregiver's point of view improve MS research?



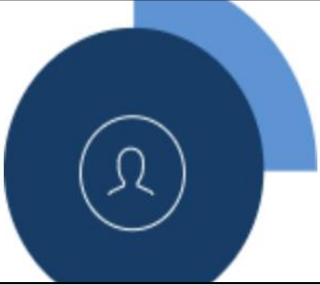
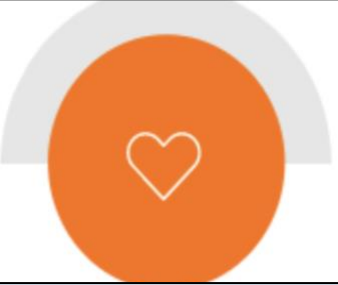

## iConquerMS CAREGIVERS

Patient-focused drug development (PFDD) is a systematic approach to ensure that patient and caregiver experiences, perspectives, needs and priorities are captured and meaningfully incorporated into drug development and evaluation.



ACP is partnering with caregivers to ensure their important insights are included in research. [iConquerMS Caregivers](#) gives individuals in this role the opportunity to participate in the design and conduct of research by sharing ideas about research topics that they care about, contributing health information to the pool of data that researchers use as a resource, and discovering research opportunities to enroll in. iConquerMS Caregivers integrates the caregiver perspective into research on two dimensions – both as an observer and partner to the person living with MS (providing valuable input on their partner's status throughout the research process), and as a person with their own needs and priorities (facilitating research that's focused on caregiver wellbeing).

## How does [joining](#) iConquerMS Caregivers make a difference?

		
<p><b>For Yourself</b></p> <p>iConquerMS is leading the field in research to better understand the needs, challenges and best ways to support caregivers. By participating, you can contribute your knowledge, experience and questions. You can learn not just from the latest findings on caregiver wellbeing, but also from others just like you!</p>	<p><b>For Your Loved One</b></p> <p>As an MS caregiver, you have the opportunity to observe the effects of the disease on your loved one and can report changes in symptoms or challenges, sometimes even more accurately than they can. Adding your insight to the base of MS research knowledge may improve daily life for all of you!</p>	<p><b>For the MS and Caregiver Communities</b></p> <p>The more people that add to the well of knowledge, the deeper and more accurate our understanding of MS, and MS caregiving, will be. By <a href="#">joining</a> iConquerMS Caregivers, you can add valuable information to that well and contribute your ideas to guide priorities.</p>



As part of the Care Partner Protocol, the CPAB is working to identify the resources that caregivers feel they've needed throughout their journey. This phase of work is primarily focused on spotlighting resources that already exist, making sure people are aware of them and making it easier to find them by bringing them together in a centralized location. In the

ACP's Care Partner Advisory Board (CPAB) is an 8-member team representing a wide variety of care partner roles, including spouses to those living with MS, a parent with a young adult daughter who was diagnosed with MS in her teens, and a woman who has provided the primary caregiving for her mother since childhood. The CPAB is working to develop a "Care Partner Protocol," which will be an online collection of resources to support MS caregivers at all stages of their journey.



future, the group may broaden this work to include developing new resources. **Want to help shape the Care Partner Protocol?** We've developed a [short survey](#) to gather the insights of MS caregivers for this important source of information.



**“Every day we wake up is a good day in our family. Every day that she is able to continue to do what she loves is a wonderful day.”**  
*Care Partner Advisory Panel Participant*

ACP is in the process of designing a Carepartner Protocol website, where people can access the resource. Two health care providers will pilot the experience of sharing the website with the caregivers they see in their practice, to assess and improve the Protocol.

MS caregivers play an indispensable role in their loved ones' lives. They may also play a pivotal role in research. Want to be a part of the movement to put patients and their caregivers at the center of research? If you are a care partner to someone with MS and haven't already done so, please consider [joining](#) the iConquerMS community with your loved one today. By sharing your experience of the daily burden of disease, your interpretation of unmet needs, and the types of research questions most important to you, you can transform the research process from one directed by sponsors and investigators to one driven by the needs of patients and their caregivers. This change in momentum has the potential to improve healthcare and outcomes not only for people affected by MS, but for the general population.



## Can spiritual wellness help MS?

If you're a member of iConquerMS, you know that we ask you about all aspects of living with the disease, including your mental health and quality of life. There is evidence that spiritual practices help people with MS with both of these and more.

### What is Spirituality?

[Dictionary.com](https://www.dictionary.com) defines spirituality as “the quality of being concerned with the human spirit or soul as opposed to material or physical things.”



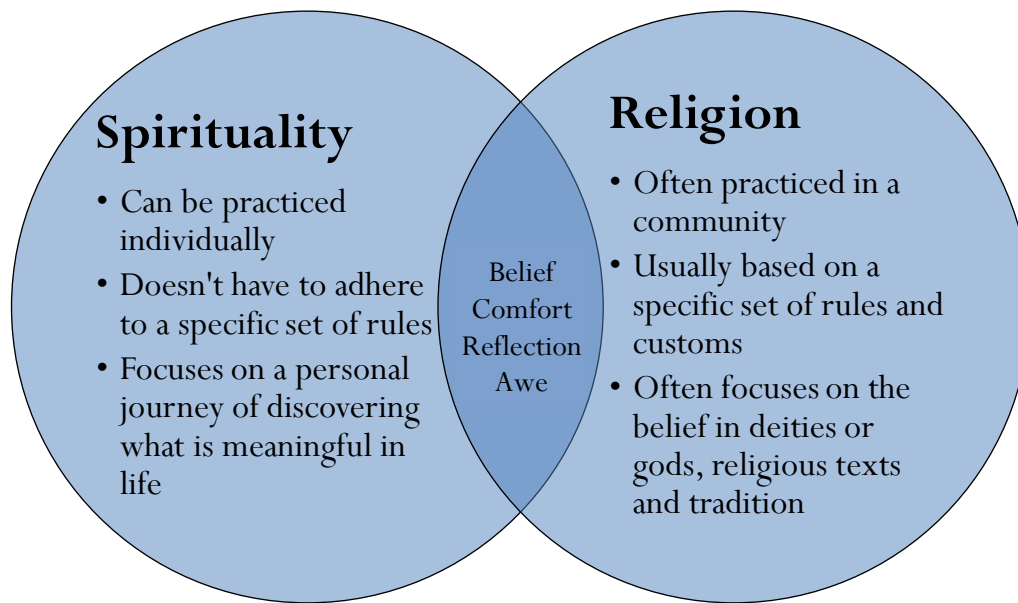
Spiritual wellness is another dimension of overall mental and emotional health.

Not everyone experiences or expresses spirituality in the same way. It is shaped by many things, including an individual's faith, values, beliefs, principles and morals. Some people may be more likely to have spiritual experiences in church, while others might have these feelings when they're spending time in nature, through art, meditation, yoga or anything else that gives their lives particular meaning.

Just as a candle cannot burn without fire,  
men cannot live without a spiritual life.”

*-Buddha*

Although there can be a lot of overlap between people who are spiritual and people who are religious, below are some key points to help differentiate between the two:



**What advantages does spirituality offer people with MS?**



There is **evidence** that spirituality helps people with MS with feelings of stress, depression and anxiety.



**Research** shows that there is a significant relationship between the spiritual wellbeing and quality of life of people with MS.



A **recent study** showed that both spirituality and mindfulness promote resilience among people with MS. Of the two, spirituality is more effective.



**Researchers** in Iran found that hope, when seen as a factor in spiritual health, can have positive and useful effects on the improvement of people with MS.



A **2020 study** showed high levels of spiritual health and self esteem protect against stress-related illness and treatment complications in people with MS. In some cases, they also alleviate frustration.

## How do I practice spirituality?

Whether you are rediscovering a forgotten spiritual path, deepening your commitment to an existing one, or exploring spirituality for the first time, there are many ways to start nurturing your spiritual side and improving your well-being.

“In order to experience everyday spirituality, we need to remember that we are spiritual beings spending some time in a human body.”

*-Barbara De Angelis*

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### Ways to add spirituality to your life:

**Pay attention to how you're feeling** - Identify what drains you and what refills you.

**Prioritize how you spend your energy and time** - Concentrate on the things that are most important to you.

**Practice gratitude** - Take a moment to notice good things in your day and be thankful for them.

**Connect to the arts** – Some people find that immersing themselves in art or music can be a spiritual experience.

**Spend time in nature** - Try taking a walk, spending time in your backyard, gardening, bird-watching, or simply looking out the window.

**Keep a journal** - Write about your thoughts, feelings and experiences.

**Try mindfulness or meditation** – As discussed in our [April 2019 newsletter](#), these practices hold many benefits for people with MS.

**Practice yoga** - According to the [National MS Society](#), yoga has a positive impact on the emotional and physical health in people with MS.

**Rely on your faith** – There is [evidence](#) that religious beliefs help people with MS keep a positive outlook on their illness and remain thankful.

**Say a prayer** - Prayer can take many forms and doesn't have to be a part of organized religion. [Research](#) shows it helps people manage pain better.

**Focus on others** - Do something each day that makes a difference to the people around you.

**Maintain balance and connection** - Nurture stable, close relationships.

**Talk with others who understand** – Come together to ask questions, give advice, and share stories with others who understand life with MS.

Spirituality is important for individuals with MS. It offers emotional strength and a positive outlook. Spiritual practices like meditation, prayer, or mindfulness can help individuals

with MS cope with the uncertainties and limitations imposed by the disease. It fosters connection, compassion and a broader perspective on life, enhancing wellbeing and quality of life for those with MS. Want to help us learn more about the benefits of spiritual practices in people with MS? iConquerMS members help to drive MS research into topics like this forward in two ways: (1) by providing valuable data about their personal experiences and (2) by proposing research questions they deem important to answer. If you're not already a member, please consider [joining](#) iConquerMS today and share your insight into spirituality today!





## August 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

ACP's Care Partner Advisory Board (CPAB) is an 8-member team representing a wide variety of care partner roles. They are working to develop a "Care Partner Protocol," which will be an online collection of resources to support MS caregivers. This month, we're highlighting how your generosity enables ACP to provide and grow this valuable resource.



**Want to help shape the Care Partner Protocol?** We've developed a [short survey](#) to gather the insights of MS caregivers for this important source of information.



As part of the Care Partner Protocol, the CPAB is working to identify the resources that caregivers feel they've needed throughout their journey. This phase of work is primarily focused on spotlighting resources that already exist, making sure people are aware of them and making it easier to find them by bringing them together in a centralized location. In the future, the group may broaden this work to include developing new resources.

ACP will use future funding to design a Carepartner Protocol website, where people can access the resource. Two practitioners will also be selected to evaluate the experience of sharing the website with the caregivers that they see in their practice and assess its impact.



[Join](#) our team and consider making a [donation](#) today! Together, we can improve the lives of everyone affected by MS!



## August 2023 iConquerMS Spotlight

### Are You an MS Caregiver? We Have a Community for You!

[iConquerMS Caregivers](#) is a new community created by and for people who are taking care of someone with MS. It offers information and resources to help answer the questions that MS caregivers often have.



By [joining](#) iConquerMS Caregivers, you can share your knowledge, experiences and questions while also benefiting from the wisdom of fellow caregivers who share similar circumstances. The more people who add to the well of knowledge, the deeper and more accurate our understanding of MS, and MS caregiving, will be.

[People-powered medical research](#) answers important questions provided by you, prioritized by you, designed by you and even implemented by you in partnership with research scientists, advocates and clinicians.



[iConquerMS Caregivers](#) is part of the [iConquerMS](#) community of people living with MS, their caregivers, scientists, doctors and others who have come together to understand MS and search for solutions.



## What you can do as a member of the iConquerMS Caregiver community?



### Be a Participant

Research studies are more than clinical trials. When you join iConquerMS Caregivers, you may be invited to:

- Fill out a survey
- Sign up for a study on exercise or meditation
- Participate in a focus group or an interview
- Report your observations about your loved one's symptoms

### Share Expertise

Science is enriched when it reflects real-world experience. Having firsthand experience as a caregiver, you may have chances to:

- Give your opinion or rate proposed topics for new studies
- Sit on a review board
- Participate in the design of a study
- Propose your own ideas for what should be studied

### Grow Our Community

iConquerMS Caregivers also offers other types of activities to make our community more informative, inclusive and welcoming. You may want to:

- Sit on one of our governing boards and help shape our projects
- Share your story on our website

**You can make a difference!** As a member of iConquerMS Caregivers, your level of participation is entirely flexible. Whether that means visiting the website to learn from others, sharing your story, filling out a survey or joining a board, your input is valuable and needed. Your engagement is warmly welcomed at any level. If you provide care to someone with MS and haven't already done so, please consider [joining](#) today!

**MAKE A DIFFERENCE.**

## August 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.

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### Multiple Sclerosis Online Course study We're Open Again!

Recruitment is OPEN! The new Multiple Sclerosis Online Course (MSOC) is starting on 24 July 2023.

If you have diagnosed MS and seek evidence-based information about MS & lifestyle, join this free & flexible 6-week online course dedicated to increasing knowledge, enhancing self-care & improving health and wellbeing of people living with MS around the world!

**Course duration:** 24 July to 3 Sep 2023

**Estimated effort:** 1-2 hr per week

**Cost fee:** Free

**Content:** Introduction to MS, diet, vitamin D, exercise, mindfulness, medication, pregnancy, family & prevention

**Eligibility:** adults with diagnosed MS

**Level:** Introductory

**What is involved:** Baseline survey about your health and lifestyle prior the course, and evaluation, 6-month, 12-month and 2.5-year follow-up surveys after the course.

**Find out more:** <https://www.msonlinecourse.com.au>

**To SIGN UP, please contact:** [neu-research@unimelb.edu.au](mailto:neu-research@unimelb.edu.au)

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## 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!

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STUDY2022-0084-MOD006  
Effective: 8/17/2023  
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](mailto: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



**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](mailto:MSDietStudy@healthcare.uiowa.edu)

→ [wahls.lab.uiowa.edu/join-study](https://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.