

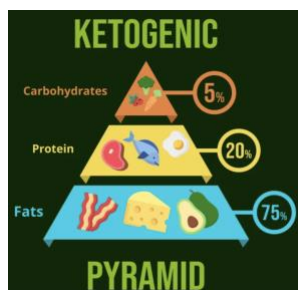
January 2023 Newsletter



MS and the Keto Diet

Making resolutions for the New Year is as traditional as making a champagne toast at midnight. One of the most common aspirations is to lose weight. The [ketogenic diet](#) or “keto” diet (KD) has gained popularity as a way to drop a few pounds quickly without having to exercise. It does this by mimicking the metabolism of [fasting](#). In

fact, the KD was developed as a treatment for epilepsy in the 1920s, after physicians observed that fasting reduced seizure activity. There is also [evidence](#) supporting its role in the treatment of several other neurological diseases, such as Parkinson’s disease, Alzheimer’s disease, migraine headaches and traumatic brain injury. Researchers are looking into the potential benefit this dietary regimen holds for people with MS.



The KD involves eating foods that are high in fat, moderate in protein and low in carbohydrates. According to the [Dietary Guidelines for Americans](#), a healthy diet derives approximately 20 to 35% of daily calories from fat, 10 to 35% from protein, and 45 to 65% from carbohydrate. In contrast, an individual on the KD consumes 70 to 80% of their daily calories from fat, 20 to 25%

from protein, and only 5 to 10% from carbohydrate. Key foods include avocado, full-fat cheeses, heavy cream, butter, whole eggs, [fatty nuts and seeds](#), bacon, beef, fatty fish, [low carbohydrate vegetables](#), and olive oil.

Typically, the body converts carbohydrates into glucose as its preferred source of fuel. However, if a person removes carbohydrate from their diet, their body is starved of glucose and switches to using fats as its source of fuel instead. This process is called [ketosis](#). Ketosis causes the liver to produce ketones (which is where the KD gets its name). These acids build up in the blood and are excreted in the urine. In small amounts, they indicate that the body is breaking down fat. However, high levels of ketones can be harmful, leading to a serious condition called [ketoacidosis](#).



The KD provides therapeutic benefit in neurological diseases through a number of different mechanisms. There is [evidence](#) that ketones have neuroprotective effects. In addition, fat is a richer fuel supply that improves the function of [mitochondria](#), which has been linked to the [survival of nerve fibers](#). High levels of the neurotransmitter, [glutamate](#), are associated with demyelination. There is [evidence](#) that the KD balances glutamate levels in the brain. [Research](#) also shows that ketones trigger a process called [autophagy](#), through which the body breaks down and gets rid of old damaged cells, making room for new healthy ones.

A number of recent studies have looked at the effects of the KD in people with MS. The results are mixed, however many have found it to be beneficial.

Research into the KD and MS

2019 – [Spanish researchers](#) studied 27 people with MS that followed a KD for four months. Results showed it lowered levels of [oxidation](#) and inflammation.

2020 – [Investigators](#) in China and Germany found that mice with the same inflammation of the central nervous system seen in people with MS saw improvement in motor function when fed with a KD. They also saw reductions in damage to the [hippocampus](#) of the brain, which governs memory and other functions and is often adversely affected by MS.

[Researchers](#) at the University of Iowa conducted a small study of 5 people with MS on the KD. Even though participants achieved ketosis on the diet, they saw no improvements in fatigue and brain function.

2021 – Researchers from the University of Miami published a [review](#) showing that people with MS who follow the KD for six months or more show evidence of potentially beneficial changes to their gut microbiome, with increases in healthy bacteria that may provide a neuroprotective effect against the damage caused by MS.

2022 – [German researchers](#) found that people with MS on a modified KD had lower levels of [neurofilament light chain](#) in their blood. This is a type of cell found in the brain and spinal cord that's considered a possible sign of neurodegeneration. Investigators suggest the KD could be used as a possible treatment for progressive MS, in which neurodegeneration is the primary problem.

[Investigators](#) at the University of Virginia, Virginia Commonwealth University and the University of Pennsylvania examined the effects of the KD in 65 people with stable relapsing remitting MS that followed the diet for 6 months. Results suggest that a KD is safe and tolerable for people with relapsing remitting MS over a six-month period. The most common side effects, which were experienced primarily during the first two weeks of the diet, were constipation (43%), diarrhea (18%), nausea (9%), weight gain (9%), fatigue (5%), worsened depression or anxiety (5%), and acne (5%). Body mass index and other measures of body fat decreased significantly over the six-month study despite no change in activity levels. Significant improvements were seen in [EDSS](#), walking and manual dexterity. Results showed a nearly 50% decline in participant-reported depression and fatigue while on the KD. Participants also reported substantial increases in physical and mental quality of life. The researchers state that larger scale studies of the KD in people with MS are needed to confirm these results and warn against following this eating regimen outside of a clinical trial and without medical supervision. It's important to note that this study was limited to people with stable relapsing remitting MS and results may not be the same for people with active relapsing remitting or progressive MS.

In 2017, German researchers began a [long-term clinical trial](#) on the KD in MS that is ongoing. Results should shed light on the effects of a KD on MS progression.



Did you know that ACP's REAL MS data, collected from members of iConquerMS, has helped researchers gain a better understanding of the effect of a low-carbohydrate diet in people with MS?

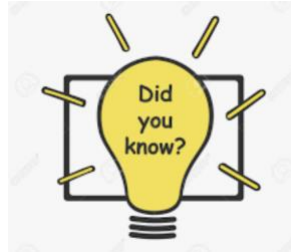
Investigators from Australia looked at wellness and diet data from over 1,100 REAL MS participants and found that a low-carbohydrate diet negatively impacted mental quality of life in people with relapsing remitting MS. Interestingly, they found it had the opposite effect in people with progressive MS. There was no association between a low-carbohydrate diet and physical or social quality of life. Their [conclusions](#) draw a number of interesting associations between other lifestyle behaviors, types of MS and health outcomes and quality of life. You can read more about this and other studies that the iConquerMS community has contributed to on the new [Research Projects](#) page of the iConquerMS website! Not already a member of iConquerMS? Please consider [joining](#) and help us move MS research forward today!

It's important to note that the KD has numerous risks, including low blood pressure, kidney stones, nutrient deficiencies and an increased risk of heart disease. There are also special considerations for people with MS. Ketosis often causes fatigue, which can compound an already significant problem for someone with MS. Changes in mobility and periodic use of steroids may put people with MS at increased risk for [osteoporosis](#). The KD not only limits some calcium sources, it can cause the body to lose calcium, making this more of a concern. Finally, MS can contribute to chronic constipation, which is also a side effect of the KD. As a result, an individual with MS may find bowel difficulties compounded if they choose this dietary regimen.



It's important for people with MS to consult their doctor before making any big changes to their diet. The completed studies into the safety and effectiveness of the KD for people with MS have been promising, but they are too small to draw broad conclusions. More research needs to be done to confirm these results. The mainstay of ACP's mission is to

facilitate research efforts into topics such as these, which have the potential to improve the health and quality of life for people with MS.



iConquerMS offers useful resources to monitor MS symptoms following lifestyle changes. These tools will graph your [REAL MS data](#) along with diary entries of any change in eating habits you've made. Check out the diary function in the iConquerMS portal!

To access the Diary function:



To see how lifestyle changes affect MS symptoms:

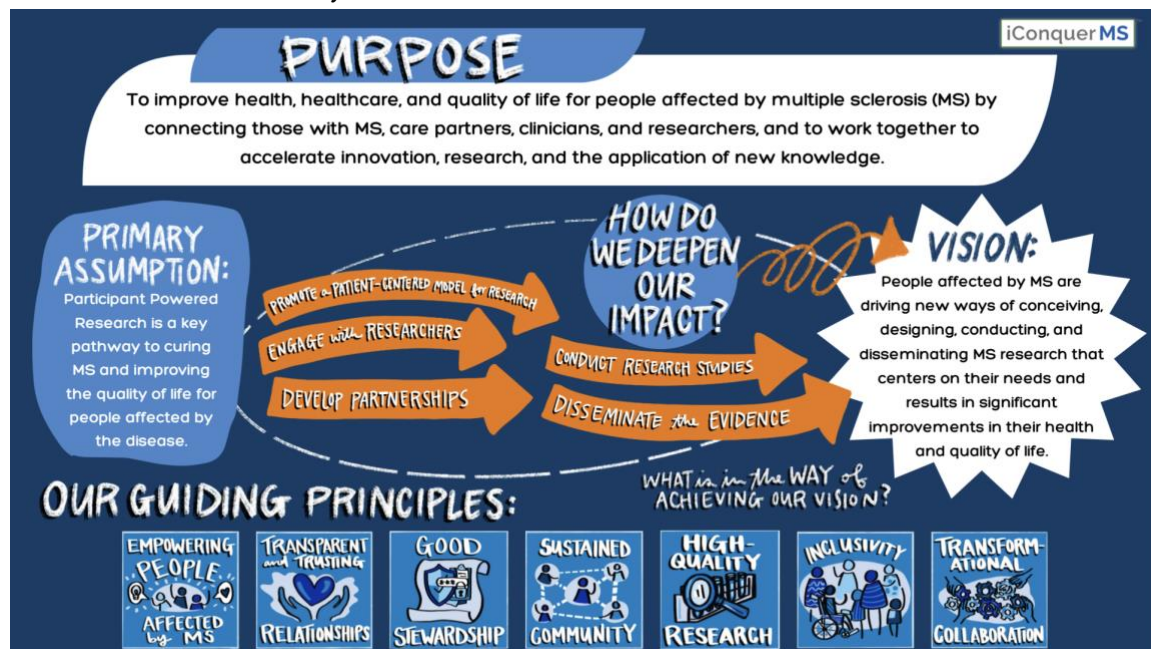


All iConquerMS members are invited to participate in REAL MS. Many of the surveys are quick and easy, some taking less than a minute to complete. If you aren't already a member of iConquerMS, please consider [joining](#) this powerful network today! Already a member? Please [log in](#) and complete your open surveys!

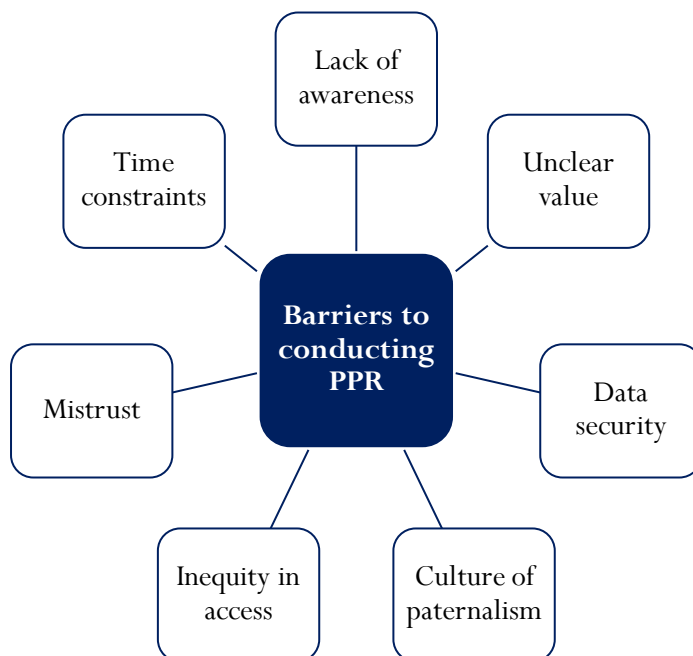
Deepening Our Impact

[iConquerMS™](#) was established to enable and accelerate MS research and other innovations with the goal of improving the health, healthcare and quality of life of people affected by MS. The initiative does this by connecting those with MS, care partners, clinicians, and researchers, and encouraging them to work together to accelerate innovation, research, and the application of new knowledge. Through iConquerMS, people affected by the disease are driving new ways of conceiving, designing, conducting, and disseminating MS research that centers on their needs and results in significant improvements in their health and quality of life.

In November, the iConquerMS governance and other stakeholders in the MS community gathered virtually at the 2022 Leadership Summit to discuss the future direction of the initiative. The key focus of this year's meeting was deepening our impact. The meeting brought together a diverse group of individuals. Almost one third of attendees were people living with MS. Other stakeholder groups present included researchers (12%), representatives from other MS advocacy organizations (11%), members of the iConquerMS governance (10%), members of other iConquerMS activities (10%), healthcare providers (7%), care partners (6%), funders (5%), and representatives from industry (2%). Most of this year's participants were from the western US, followed by the mid-Atlantic and the southwest US



This year's attendees kicked off day one of the Summit by reviewing iConquerMS's purpose, vision and guiding principles. They celebrated the [progress](#) the initiative has made increasing the awareness of and engagement in [participant-powered research](#) (PPR). Participants divided into stakeholder groups and considered the following questions – “What gets in the way of your group fully committing to PPR?” and “What needs to change so PPR can become the rule and not the exception for your stakeholder group?” A number of key barriers to conducting PPR emerged from these discussions, which are summarized below. Day two was focused on pursuits that would break down these barriers and further advance PPR.



Summit attendees had a robust discussion about making PPR mainstream. One pathway forward involved transforming the education of healthcare providers, involving people affected by MS in continuing education presentations. This would get physicians used to considering the patient perspective, putting them in a better position to conduct PPR. The group stressed the importance of spreading the word about PPR with a unified voice (in collaboration with all MS stakeholders). One possible way to do this would be to create educational resources describing the nature of PPR and make them available electronically, or in the form of pamphlets for waiting rooms and pharmacies.

The group also talked about ways to promote PPR in the research community. One suggestion was to make the inclusion of the patient perspective a funding requirement for prospective studies, targeting organizations that generate a lot of research funding (for example, foundations and pharmaceutical companies). A legislative approach was also proposed, which would involve appealing to Congress to put pressure on government funding agencies to comply with this requirement. All agreed that educating researchers and funders about the value of PPR and how it streamlines the research process should be a big part of this effort.

Raising awareness about iConquerMS was another main focus of this impactful weekend. The importance of building trust in the initiative (and research in general) was emphasized. The group talked about different ways to promote iConquerMS, for example, by connecting with other MS organizations, through social media, and asking current members to spread the word about the initiative.

To boost enrollment, participants in this year's Summit thought it would be helpful to make iConquerMS more personal and welcoming. Creating "advocate pods" is one possible way to do this. iConquerMS is very large network that may seem overwhelming to some. Creating smaller communities, each with its own advocate, would allow members to work in smaller groups. Pod advocates could follow up with individuals that fall silent to see how they are doing and if they need any assistance. These micro-communities would create an increased sense of fellowship, engender greater trust in the initiative and enable more consistent data collection. Another suggestion was to focus on accessible topics, such as lifestyle habits, as a gateway or entry point into iConquerMS. Easy, relevant topics like this could engage people and they would have the opportunity to participate in more complicated or technical studies down the line. The group also explored alternate ways of collecting data (for example, using [wearables](#)) to make participation easier.



Summit attendees discussed the importance of expanding research recruitment efforts to low-income populations. One idea was to furnish the tools necessary for participation, such as cell phones (or other devices) and internet access, to those that need them. The end result would be increased access to PPR opportunities (like iConquerMS), other MS resources and better overall healthcare. An offshoot of this conversation focused on creating training programs for those that are not familiar with devices. The group proposed reaching

out to existing programs that provide this type of assistance for guidance and seeking funding for this effort from our MS coalition partners, telecommunication companies and government agencies.



Conveying information to research participants and collecting their feedback are two important aspects of PPR. Summit attendees agreed that a participant newsletter would be an excellent means to accomplish both of these goals. The consensus was that the ideal format would be a single page that could be sent by mail or

electronically on a cadence that makes sense for a given study. It should be educational (including hyperlinks for language that people might not understand) and visually pleasing. Including such a publication in research budgets and protocols would pave the way for its distribution.

The iConquerMS community has made many studies possible over the years. Making research results available and understandable has been a continuing thread at past Leadership Summits. Our new [Research Projects](#) page is a wonderful byproduct of last year's meeting. It is a convenient place to track the status of studies and review their findings. The general consensus this year was that not enough people know about this wonderful resource and all agreed to help spread the word about it within their networks. With regard to the dissemination of research results in general, attendees agreed that getting funders to approve related costs as part of a PPR budget would help ensure that dissemination protocols are in place.



One [breakout session](#) at this year's Summit focused on transforming healthcare and medical research to be more holistic. Participants talked about [social determinants of health](#) and the importance of fresh air, green spaces, the availability of healthy food. With regard to research, the consensus was that we need to work together with other disease groups and focus more on the prevention of disease. A proposed way to advocate for this change was to be more present at scientific meetings, challenge the status quo and speak up on behalf of those living with chronic illness.

January 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



**Minority Engagement
in MS Research**

This month, we're highlighting how your generosity enables ACP and our iConquerMS network to disseminate research results in actionable and understandable ways.

ACP/iConquerMS programs that bring the latest in MS research to you!



The [Chat with Chat webinar series](#) provides a glimpse at the researchers working with iConquerMS, what they study, and how their work will benefit people with MS.



The [research projects](#) page of the iConquerMS website provides summaries of some of the projects conducted with and by iConquerMS.



The [ACP newsletter](#) is one of the vehicles through which we keep you informed about new findings in MS research and much more!



Looking forward, we're in year one of a two year capacity building award to enable iConquerMS to disseminate the results of the [PCORI funded MS projects](#)! Stay tuned!

Thanks to your support, ACP and iConquerMS are able to spread the word about current MS research findings and other MS-related topics. We enable people affected by MS to use the most up-to-date information to inform their healthcare decisions in collaboration with their healthcare providers. Join our team and consider making a [donation](#) today! Together, we are working to improve the health and quality of life for everyone in the MS community.



January 2023 Research Spotlight

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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Our Questions Have Power

iConquerMS Spotlight

**Want to learn about research that's
being done through iConquerMS?**

**Don't miss the Chat with Chat
webinar series!**

The Next Steps Committee of iConquerMS has launched a new webinar series called “Chat with Chat” and you’re invited! Hosted by our research collaborator Chat Ngorsuraches, these conversations provide a glimpse at the researchers working with iConquerMS, what they study, and how their work will benefit people with MS. 10 episodes of Chat with Chat have aired to date. In case you missed or would like to revisit any of them, they are listed below:



In [Episode 1](#), Chat spoke about his own research into the aspects of MS drugs that people value the most.

In [Episode 2](#), Chat spoke with Nina Bozinov, MD MS, about "Measuring the Quality of Life of People With MS: Findings From the REAL MS Study."

In [Episode 3](#), Chat spoke with Farrah Mateen, MD PhD, about what we've learned from iConquerMS about COVID-19 and MS.

In [Episode 4](#), Chat spoke with Farren Briggs, PhD ScM, about “COVID-19 vaccine safety: A study from iConquerMS data.”

In [Episode 5](#), Special guest Hollie Schmidt spoke with Mitch Wallin, MD MPH, about “Telemedicine and MS: Perspectives from Patients and Health Care Providers.”

In [Episode 6](#), Chat spoke with Annabel Decamps from Icometrix, a company that develops software and services that help people view, store, and analyze medical images such as MRIs.

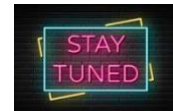
In [Episode 7](#), Chat covers the topic of how (and why!) to become a research accelerator. Hear from people living with MS, researchers, and members of the iConquerMS project team to learn how YOU can accelerate MS research!

In [Episode 8](#), Chat spoke with Sarah Minden, MD, PhD from Brigham and Women’s Hospital about “Use of complementary and alternative medicine (CAM) by members of iConquerMS”.

In [Episode 9](#), Chat spoke with Nupur Nag, PhD from the University of Melbourne, Australia about “Assessing the impact of lifestyle behaviors on health outcomes in people with MS.”

In [Episode 10](#), Chat spoke with Deborah Miller, PhD, LISW from Cleveland Clinic Lerner College of Medicine about “Insurance coverage for people with MS – where are the gaps?”

A heartfelt thank you to Chat and his colleagues for making this educational resource possible. Stay tuned for future episodes!



RESEARCH OPPORTUNITIES



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!



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

JOIN TODAY to receive a **FREE** 6-week online course in March – April 2023:

<https://www.msonlinecourse.com.au>

Module 1 – Introduction to MS

Module 2 – Diet & MS

Module 3 – Sunlight & vitamin D

Module 4 – Exercise & MS

Module 5 – Stress management

Module 6 – Medication & family prevention

Module 7 – Change your life, for life

The course is open to people with MS worldwide, providing you the opportunity to connect with other MSers and play an important role in research to improve how we understand and manage this disease.

Contact Associate Professor Sandra Neate for questions or concerns:

neu-research@unimelb.edu.au



Help us understand the benefits of a home-based exercise program for African Americans with MS!

Research opportunity, University of Illinois – Chicago. This study involves the remote delivery of a 16-week exercise training program for rural-residing African-Americans with Multiple Sclerosis (MS).

Benefits of participating

- Learn about methods of improving your health and wellness
- Contribute to ongoing research on African Americans with MS

Eligibility

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

For more information:

Contact Edson Flores

(833) 727-1887

enrl@uic.edu

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



You are invited to participate in a research study comparing the effects of three diets!

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 attending the 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 to 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



**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.