

July 2023 Newsletter



The Other Side of MS

It's vitally important to support caregivers and pay attention to their needs, as they are the backbone of many families. iConquerMS continues to expand its research collaborations to include MS caregivers, in hopes of easing their burdens and improving MS research in the process.



According to a [survey](#) developed by ACP and [UsAgainstAlzheimer's](#), the top three challenges experienced by caregivers are **uncertainty about the future, stress, and not having enough "me" time**. Other common problems include not getting enough sleep, the inability to leave home, safety, and financial concerns. 77.5% of caregivers do not have sufficient access to the help and support that they need.

In MS, the role of the caregiver is constantly changing. As MS caregivers are generally unable to anticipate the onset of a relapse, the progression of the disease, or even the functional ability of their loved one over the course of a day, the resulting ups and downs can be stressful and draining for everyone.

"A good day is when nobody's getting hurt, nobody's falling down and everyone's taken care of."

Care Partner Advisory Panel Participant



In 2012, the [National Alliance for Caregiving](#) (NAC) conducted a [survey](#) of 421 individuals who provided care to a friend or family member with MS. Results indicate caregivers spend an average of 24 hours per week taking care of their loved one (more in cases where the care recipient experienced frequently changing symptoms).

According to the NAC survey:

The most common negative impacts of providing care were financial (due to unemployment), being unable to engage in hobbies, and issues with mental health.
Almost half of respondents felt they didn't have a choice taking on caregiving responsibilities. Those that did felt fewer negative and more positive impacts.
Caregivers providing care to those with cognitive impairment were more likely to feel negative impacts from their role.
Many were constantly worried that their care recipient would take a turn for the worse and wished their symptoms were more consistent or stable.
Half of respondents reported being physically exhausted.
Nearly one third were physically injured as a result of providing care.

Caregiver burden is “the strain or load borne by a person who cares for a chronically ill, disabled, or elderly individual.” Increased caregiver burden can have a profound impact on the care provider and recipient. Without proper training (for example, lifting or transfer techniques), the physical aspect of providing care to someone with MS can potentially lead to injury. The cognitive effects of the disease (problems with memory, attention or information processing) are far reaching. Both of these add to caregiver burden and have a ripple effect on the lives of those involved.

According to a 2011 study, caregiver burden is directly related to:

Being male or assisting a male with MS

Time spent providing assistance

The care recipient's overall health

The care recipient having bladder dysfunction

The caregiver having limited ability to participate in hobbies

[Research](#) suggests that the cognitive symptoms of MS have a greater influence on caregiver distress (and reduced quality of life) than physical disability. Results show depression in a person with MS directly impacts depression in their caregiver.



“That’s our role as partners, I’m there to help where possible.”

Care Partner Advisory Panel Participant

Recognizing that every situation is unique, people are generally forced into different roles when chronic illness or disability strikes. The individual providing assistance typically takes on added responsibilities, while the recipient loses independence. Providing care to a loved one can bring individuals closer. However, it can also put a strain on relationships, especially if changes aren’t welcome and affect future plans. Adjusting to new roles is challenging, but adjusting to unwanted ones is even more so.

[Danish researchers](#) found MS significantly affects the probability of remaining in the same relationship. Data shows the probability of a marriage continuing after five years is 86% for people with MS versus 89% in healthy controls. After 24 years, the probability drops to just 33% for people with MS compared with 53% in the control group. A [2009 study](#) found there is a more than six-fold increase in the risk of divorce if the affected spouse is the woman (21% versus 3%, if the man has MS). [Investigators](#) in Sweden concluded the disease is associated with a 21% higher risk of divorce among men, but not women.

While MS caregivers include parents, children, friends, and neighbors, [research](#) shows up to 70% are the spouse of the person with MS.



“I’ve never known her to walk but for me it was love at first sight so you just have to find a way to make a marriage between 2 people with MS work. We’ve been married for over 17 years now.”

Care Partner Advisory Panel Participant

Caregiver burnout is the unfortunate result of high levels of burden over an extended period of time. Understandably, this has dire consequences for administering care.



Recognizing the signs of caregiver stress is important. Physical signs may include fatigue, exhaustion, trouble sleeping, decreased strength and endurance. One should also watch for psychological or emotional symptoms, such as irritability, anger, depression, inability to concentrate, memory problems, social withdrawal, and feelings of isolation.

“My entire life revolves around taking care of her.”
Care Partner Advisory Panel Participant

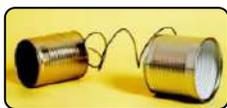
Helpful tips to avoid caregiver burnout



Know your strengths, where you need help and the resources available to you.



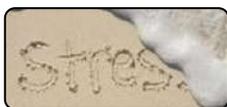
Make sure you have a support system to help you through difficult and lonely times.



Good communication is key. Don't be afraid to ask for help.



Educate yourself. Knowing more about MS symptoms, treatment options and side effects can help you feel more confident and in control.



Have ways in place to reduce stress.



Staying organized can help keep stress to a minimum and free up more time to do the things you enjoy.



Don't forget to take care of yourself!

iConquerMS

CAREGIVERS

Are you an MS caregiver? [iConquerMS Caregivers](#) is an ideal resource for you! The initiative 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. You'll find information and resources to help answer the questions that MS caregivers often have. You'll discover opportunities to participate in research designed to improve the lives of MS caregivers and the people they care for. 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 that add to the well of knowledge, the deeper and more accurate our understanding of MS will be. If you provide care to someone with MS and haven't already done so, please consider [joining](#) the iConquerMS community with your loved one today!

Other Resources

There are a number of other excellent resources for caregivers that offer information and support free of charge:



The [Family Caregiver Alliance](#) provides state-by-state resources, including respite providers.



The National MS Society's [MS Navigators program](#) connects caregivers to valuable resources



The Society also offers the guidebook, [Caring for Loved Ones with Advanced MS: A Guide for Families](#)



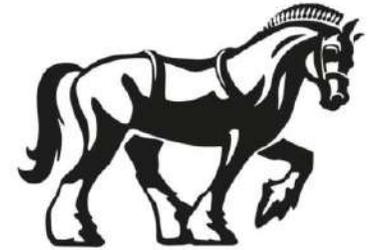
The Caregiver Action Network offers an online forum called [Care Chat](#) for caregivers to support one another



Can Do MS offers the [Embracing Carers webinar series](#) that addresses many relevant topics

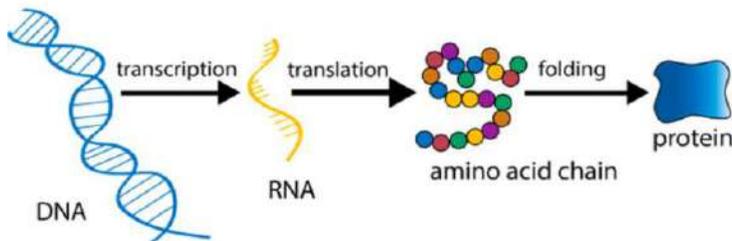
The ACP Repository – A powerful tool in the next generation of MS research!

Proteins are the work horses of the human body and its cells, determining both structure and function. The key to discovering a cure for MS may lie in studying the components of proteins and how they interact. [Omics](#) research is an emerging field that aims to do just this. The ACP Repository is a growing, vital resource for these studies.



Gene Expression

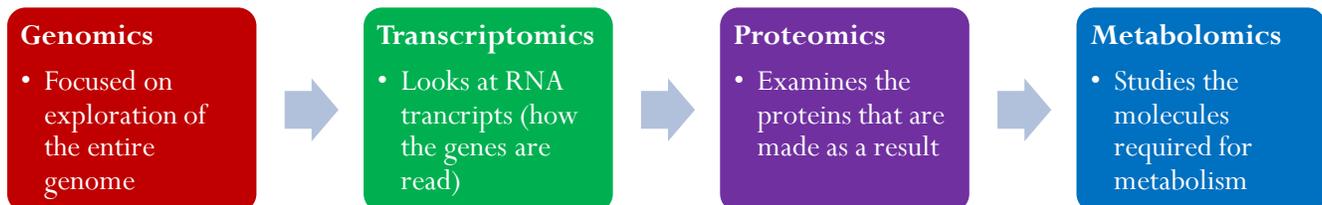
[Amino acids](#) are the building blocks of proteins. They are made through a 2-step process. A cell's genetic instructions (which are made up of [DNA](#)) are copied, or [transcribed](#), into a temporary molecule called [messenger RNA](#) (mRNA). mRNA is then [translated](#) into a sequence of amino acids.



The [genome](#) is the same in every cell, however each cell transcribes its own sections of the genome based on what type of cell it is. The pattern of gene expression (the set of genes a cell transcribes) determines the cell's function. These gene expression patterns are altered during disease. Studying them can yield valuable insights into cell and tissue specific biological pathways and how they are involved in disease.

The [omics](#) sciences share the goal of identifying, describing, and quantifying all of the molecules that contribute to the form and function of cells, and how they correlate to disease in humans.

Branches of Omics Research





The ACP Repository is an open-access resource of blood samples and data from over 3,200 participants for the study of MS and other demyelinating diseases. Accompanying each sample are approximately 50 pages of self-reported personal information and clinical data, which is collected on a questionnaire, or case report form (CRF).

Investigators using ACP samples and data in their studies must return their research results to the Repository database for the future benefit of all researchers. As we continue to share ACP biosamples with researchers around the world, the Repository database contains a growing inventory of returned genomic, transcriptomic and proteomic datasets. Because some samples have been sent to multiple research teams, the returned research results contain new and important information that can be combined to explore new hypotheses and ideas. These overlapping datasets on the same individual represent exciting opportunities for “virtual collaborations” in which a researcher could use the results from another research study to inform their own work, do additional analyses, or a combination of both. These virtual collaborations are just one of the aspects of the ACP Repository that makes it a vital resource for MS research. ACP is compiling an inventory of the returned datasets and their overlaps (the samples they have in common), and will approach partner scientists to inspire new collaborations and accelerate and advance MS research.

Comparing overlapping datasets can provide valuable insights into MS disease mechanisms, better diagnostic techniques and treatment methods, especially when combined with the detailed CRF information.



[Regulatory RNAs](#) are a second class of RNAs that do not encode proteins. Instead, they control protein synthesis. Regulatory RNAs and mRNAs work together in this process. mRNAs are the couriers that carry the instructions for making proteins from the genes to the [ribosome](#) (where the proteins are made). Regulatory RNAs oversee the gene's activity and make sure things happen as they should, like supervisors or managers. By analyzing regulatory RNAs, scientists can gain insight into all of the genes they control, making this a more efficient way to study disease mechanisms.



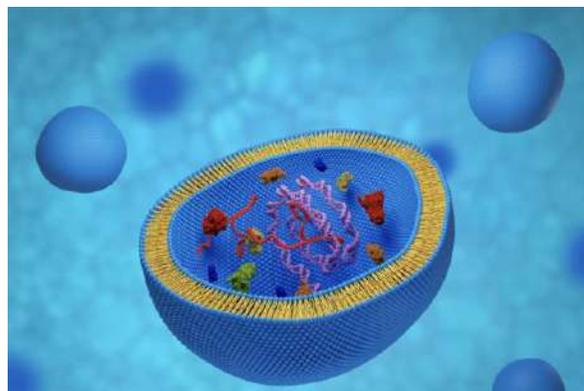
Researchers have identified specific MS-related regulatory RNAs like [long non-coding RNAs](#) (lncRNAs) and [microRNAs](#) (miRNAs) using ACP Repository samples. Future collaborations could further analyze these returned data to shed more light on immune response, MS disease progression, repair and recovery, and lead to new insights about MS. This is an emerging area of MS research that ACP Repository resources could be instrumental in supporting.



In 2018, the Regeneron Genetics Center did a special kind of testing on the DNA samples from the ACP Repository. They looked at a small part of the DNA called the [exome region](#). This region contains only about 2% of a

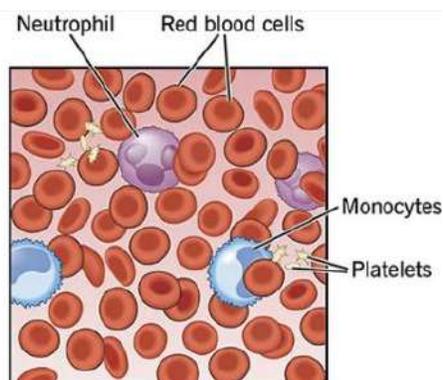
person's DNA, but it's important because it contains the instructions for making proteins. The other 98% of the DNA doesn't make proteins, it has other important jobs which include encoding regulatory RNAs (which, as mentioned above, manage how genes work). To learn more about these regulatory RNAs and what they do, ACP is looking for partners to do a more detailed test called [whole genome sequencing](#). This test will look at all of the DNA in these samples, not just the small exome region. It will give them a better understanding of these non-coding RNAs and how they control gene activity. By studying the whole genome, ACP hopes to uncover more secrets about these important regulatory RNAs and how they work with the rest of our DNA. This can help us understand how genes are controlled and how they affect our health and well-being.

An [exosome](#) is a tiny sac-like structure that is formed inside a cell that contains some of the cell's molecules, including proteins, DNA and RNA. Exosomes are released into the blood by many types of cells and travel throughout the body. Researchers are using ACP samples to look at miRNAs in exosomes. Future studies could examine the other molecules in these structures. This groundbreaking work could be the basis for new diagnostics in the future.



What are the limitations of ACP Repository resources?

ACP Repository samples are all whole blood samples that contain a mixture of multiple cell types. Results for RNA and protein analysis may be complicated as a result. It may only be possible to see the most prevalent molecules and the rare ones may be hidden. [Single cell sequencing](#) would allow us to see all cell types. If an investigator chose to do this technique in the future, their results would be added to the Repository database.



The multiple cell types in whole blood samples

The information in the ACP Repository is not MS-exclusive (it also includes samples and data from other demyelinating disorders and healthy controls). Are there sufficient overlapping MS datasets to produce any useful insights?

Some data in the Repository database is derived from older technology. Will it yield useful information?



Repository 2.0 – Where do we go from here?

A new collection of blood samples from iConquerMS members would not only refresh the ACP Repository's existing inventory, it would also add samples from individuals that have taken newer MS treatments. The samples could undergo newer methods of analyzing peripheral blood, such as single cell sequencing. Blood samples and accompanying patient-reported outcomes ([PRO](#)) data could be collected over time to give a detailed picture of each participants' MS journey.



The people who contributed samples and data to the ACP Repository (perhaps you are one of them!) knew that they were helping researchers conduct studies into the causes, mechanisms, and treatment of MS and other diseases. What they (you) might not have known is that they (you) were adding to what has since become the largest and most diverse collection of data about MS in the world. No other data set that combines biosample analyses, personal and clinical data exists to rival what together we have built. Moving forward with a prospective collection of samples and data from iConquerMS participants would enrich this powerful resource further. Its potential to help unlock the underpinnings of MS, new diagnostics, treatments and cures is unparalleled!



July 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

The key to discovering a cure for MS may lie in studying the genetic underpinnings of the disease. The [ACP Repository](#) is a growing, vital resource for these studies. This month, we're highlighting how your generosity enables ACP to provide and, potentially, grow this valuable resource for researchers working to understand the disease and search for solutions.



Researchers have identified specific MS-related gene regulators using ACP Repository samples. Future collaborations could further analyze these returned data to shed more light on the immune response, MS disease progression, repair and recovery.

The ACP Repository is an open-access resource of blood samples and data for the study of MS and other demyelinating diseases. Investigators using ACP samples and data must return their research results to the Repository database for the future benefit of all researchers.



The ACP Repository has become the largest and most diverse collection of data about MS in the world. Moving forward with a prospective collection of samples and data from iConquerMS participants would enrich this powerful resource further. Its potential to help unlock the underpinnings of MS, new diagnostics, treatments and cures is unparalleled!

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



July 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!

July 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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Our Questions Have Power



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



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 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:

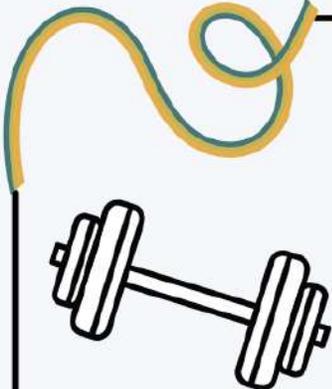
- Multiple sclerosis diagnosis
- Major depressive disorder
- Internet and e-mail access
- Willingness to complete training
- Physically inactive
- Able to walk
- 18-64 years of age
- English as a primary language
- Live within 100 miles of Chicago

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



For more information,
contact Edson Flores

(833) 727-1887

enrl@uic.edu

Keyword: TEAAMS

<https://projectteaams.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.