

# December 2022 Newsletter



## Looking Back at 2022

The ACP newsletter is one of the vehicles through which we keep you informed about MS-related topics, new findings in MS research and news from ACP. We've covered a wealth of information over the last 12 months. As the year draws to a close, we'd like to review some of our newsletter topics from 2022. For those who would like to revisit any of them, they are just a click away!



Are you thinking about New Year's resolutions and healthier living? Even small positive changes can help!

- ◆ **Keep your smile white and bright!** Learn why [oral health](#) is so important for people with MS and follow the controversy over the safety of silver fillings.
- ◆ **Revisit what's in your pantry!** Understand how eating [processed foods](#) may affect your MS.
- ◆ **Is skipping meals a good idea?** Discover ongoing research into the benefits [intermittent fasting](#) may hold for people with MS.

## SYMPTOMS



MS affects everyone differently and causes a wide range of symptoms, some more common than others.

- ◆ **Having difficulty with your vision?** In February, we explored [nystagmus](#), an eye movement disorder that is sometimes associated with MS.
- ◆ **Is keeping your balance an issue?** Read more about two related symptoms that over half of people with MS struggle with – [dizziness and vertigo](#).
- ◆ **Are you living with chronic facial pain?** Our August newsletter provides insight into [trigeminal neuralgia](#), including ways to manage it.
- ◆ **Can't stand the heat? You're not alone!** [Read about](#) a challenge the vast majority of people with MS face – heat sensitivity.
- ◆ **Does MS leave you feeling on the edge?** You may be able to learn some new ways to restore your inner peace [here](#).
- ◆ **Did you know that Lyme disease and MS are often confused?** [Learn](#) the differences between the two conditions and why it's important to distinguish between them.
- ◆ **Is it MS, or am I just getting older?** In November we covered [late-onset MS](#) in individuals over the age of 50.



It's important to diagnose MS as early as possible, so that treatment can begin and, ideally, prevent the progression of neurological damage and disability.

- ◆ **Are you curious about how MS is diagnosed?** In August, September and October we did a series on the tools that neurologists use for this purpose: the [McDonald Criteria](#), [magnetic resonance imaging](#) and [lumbar puncture](#). Read on to learn more!



MS researchers are making headway toward understanding many facets of MS. These advances have potential to improve quality of life for everyone living with the disease and bring us closer to a cure.

- ◆ **Helping to make REAL progress toward a cure!** Take a closer look at [REAL MS](#), including some advances in MS research that it has enabled to date.
- ◆ **A catalogue for a cure?** Introducing the [MSDA Catalogue](#), an exciting new tool for MS researchers!
- ◆ **Is Epstein Barr virus linked to MS?** Hear the details of a recent [Harvard study](#) that provides the strongest evidence yet that this is true.
- ◆ **New genetic clues on MS risk.** Explore [new research](#) that shows people with a higher hereditary risk of MS are likely to develop the disease at an earlier age.
- ◆ **Just how expensive is MS?** Our May newsletter dives into research to investigate the [rising cost](#) of MS care, including a number of resources designed to help.
- ◆ **Have you ever considered using Cannabis to relieve your MS symptoms?** Read about [Sativex](#) and the research currently underway to gain its FDA approval in the United States.



Interested in what's happening at ACP?

- ◆ **Meet the man behind “Chat with Chat!”** Get to know [Surachat Ngorsuraches](#), his enthusiasm and commitment to serving the MS community are inspiring!
- ◆ **The ACP team continues to grow!** Introducing our newest staff member, [Mark Gilliland](#). His expertise as a data professional is a great asset in all of our initiatives!

◆ **Who's at the helm of ACP?** Our Board is a diverse group of generous individuals with different schooling and expertise, each of whom plays a key role in moving ACP and MS research toward a cure. Read about them [here!](#)

According to ACP's Chief Research Officer, Robert McBurney, ACP's fundamental approach can be stated as "we don't do the research, we create much-needed resources and capabilities that make MS research go faster and better." We're grateful for the many ways that our partners, donors and volunteers have given of their time, talents and resources to help us do this work. Together we are accelerating research for all affected by MS, bringing us closer to a cure. We look forward to new possibilities in the upcoming year. In Hollie Schmidt's words (ACP's VP of Scientific Operations), "There is always something new to learn, some new challenge to address, or some new breakthrough to celebrate. Much progress has been made in MS in the past couple of decades, and there is still much left to do. It's exciting to be a part of it!" Stay tuned, and look for updates in future newsletters!



## 2022 Highlights from iConquerMS



People living with MS are the heart and soul of iConquerMS. A primary objective of the initiative is to enable all people living with MS to drive, shape, and accelerate research. Network members are able to not only contribute data about their MS experience, but also steer the direction of research by contributing their ideas. Ideally, tens of thousands of people from all parts of the country, from all backgrounds and ethnic groups, and of all ages and stages of living with MS will participate. This diversity will create a rich, interactive resource for MS research. This innovative program has made significant progress toward realizing this vision. In 2022, the network has grown to over 8,500 adults living with both relapsing remitting and progressive forms of MS. Here's a look at some of the other milestones we've reached in the past year:



### Expanding and Enriching the Network

- ◆ **Welcoming [children, adolescents and their family members](#) to iConquerMS!** Support for pediatric MS within the network is being designed and implemented based on [input](#) from individuals in this very important age group and their loved ones. We look forward to partnering with pediatric MS researchers and healthcare providers to support their work!
- ◆ **Supporting MS caregivers** - Care partners are the backbone of many families. We have a few initiatives underway to support those in this important role. With help and [feedback](#) from MS caregivers, we are expanding iConquerMS to include MS caregivers in the network (stay tuned for the launch!). We are also working to develop a “toolkit” to provide access to resources to address many of the situations caregivers face. Are you an MS caregiver that wants to share your insights? Take a short survey [here](#)!

## Investigating Topics That Matter to the MS Community



- ◆ **Working together to defeat COVID-19!** The [COVER-MS study](#), conducted via iConquerMS, provided important information about the safety of COVID-19 vaccination in people with MS. **The study is still open** and we are now exploring vaccination efficacy by measuring antibody response. You can learn more about this sub-study [here](#). Interested to learn more? Email us at [info@iConquerMS.org](mailto:info@iConquerMS.org).
- ◆ **Helping people with MS succeed in the workplace** - Our newest research survey gathered information about work-related challenges and resources for people with MS. The results will be used to develop personalized tools to help them make employment decisions and access resources to stay employed.

## Advancing Participant-Driven Research



- ◆ **Our Questions Have Power!** iConquerMS members not only help conquer MS by confidentially sharing their health information, they can also power MS research with their questions and priorities. The [Our Questions Have Power](#) program was launched in 2021 with an initial focus on COVID-19. Earlier this year, we extended it to include a second topic: MS symptoms and their management and treatment. iConquerMS participants are invited to share the questions on this topic they think should be studied and to vote on questions submitted by others. These questions will be shared with people affected by MS, researchers, healthcare professionals, advocates, and funders – and, together, we'll work to launch research studies to answer them.

## Disseminating Research Results



- ◆ **Check out a new iConquerMS website feature!** The iConquerMS community has made [many studies](#) possible over the years. Our new [Research Projects](#) page is a convenient place to track their status, see summaries of the work being done and review research results!
- ◆ **Want a chance to connect with MS researchers?** New this year, the Chat with Chat webinar series enlightens us about the researchers working with iConquerMS, what they study and how their work will benefit people with MS. [Ten episodes](#) have aired to date. We thank Chat Ngorsuraches for hosting this exciting program and look forward to what he has in store for us in 2023!

[iConquerMS](#) members are part of a community that is making a difference! Not already an iConquerMS member? Please consider [joining](#) today. Together, we can make an even greater impact advancing relevant, participant-driven MS research in 2023!



## **December 2022 Donor's Corner**

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

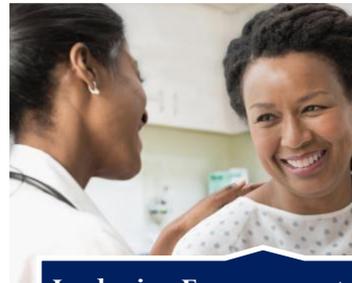
**Your generosity supports ACP's initiatives to accelerate MS research for quicker diagnosis, more effective treatments, and a cure for all living with the disease.**



**ACP Repository**



**iConquerMS**



**Inclusive Engagement  
in MS Research**

This month, we're highlighting how your generosity enables the iConquerMS network to execute on research that matters most to people with MS.

People affected by MS have many unanswered questions about how to treat and manage the disease, and how to improve their health and well-being. The COVID-19 pandemic raised even more questions for people living with MS around their risks related to the disease, vaccine safety and efficacy, and many other topics.

Thanks to your support, the iConquerMS network was poised and ready to facilitate the research needed to answer these questions.

The [COVER-MS study](#) provided important information about the safety of COVID-19 vaccination in people with MS. We are now exploring vaccination efficacy by studying antibody levels through an exciting [sub-study](#) that was launched in September. We're also developing new surveys and planning new analyses to explore other COVID-related topics, including long COVID, access to Evusheld (COVID-19 preventive therapy), breakthrough COVID infections and the impact of COVID-19 vaccines on MS symptoms. By launching and conducting research studies quickly and effectively, focusing the research on the topics that matter most to people living with MS, and making the studies available to the 8,500 (and

growing!) members of iConquerMS, the network is making a positive impact on the health and quality of life for people affected by MS. We're just getting started, too! Stay tuned for more people-powered research through iConquerMS!



## December 2022 Research Spotlight

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Our Questions Have Power **episodes of Chat with Chat:**

## iConquerMS Spotlight

**Want to know more about insurance coverage for people with MS? Don't miss the latest Chat with Chat webinar!**

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.



In December, 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?" Anyone interested in hearing this conversation can find the latest Chat with Chat webinar (Episode 10) [here](#).

**episodes of Chat with Chat:**

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."

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



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# 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.



## **Make Your Voice Heard!**

Take our survey and share your first-hand experience with MS treatments!

We are reaching out to ask you to complete a short survey being conducted by the MS Coalition, a network of MS organizations including Accelerated Cure Project that advocates for people affected by MS. This survey asks about how people make treatment decisions about MS medications and other perspectives about the value of medicines. The survey will take no more than ten minutes to complete.

We are conducting this survey because the Institute for Clinical and Economic Review (ICER) is currently evaluating disease-modifying therapies for MS. Insurers may use ICER's recommendations to make decisions about how they cover MS medications. This could potentially improve or restrict people's access to MS medications. We want to add the perspectives of the MS community to their assessment.

The survey is open until January 10.

To complete this survey in English, click  
here: <https://form.jotform.com/223524286804154>

To complete the survey in Spanish, please click  
here: <https://form.jotform.com/223524081667154>

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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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## **New REAL MS Surveys! Sharing Your Experience Matters**

New REAL MS surveys have landed on your iConquerMS dashboard! Please [visit the site](#) today and fuel MS research by completing your open surveys.

In addition to accelerating MS research with your data (reason #1!), we'll also be able to tailor upcoming research opportunities for you (reason #2!). Knowing information about your demographics and MS history means that when the right opportunity comes along, we can reach out to YOU!

**How to accelerate MS research (and make sure we can contact you with additional research opportunities):**

1. Visit your [dashboard](#) (you'll be prompted to log in)
2. Click on the "View and Complete My Research Surveys" button
3. Complete your first open survey
4. Repeat steps 2 and 3 until you have no more open surveys!

If you run into any problems or have any questions, just send us an email at [info@iConquerMS.org](mailto:info@iConquerMS.org). Thank you for your participation! Your data – especially your REAL MS data – has power! Your health information is important even if you think things haven't changed much in the last few months.

Visit My  
Dashboard

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## **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](mailto:enrl@uic.edu)

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

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

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**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.