

# December 2023 Newsletter



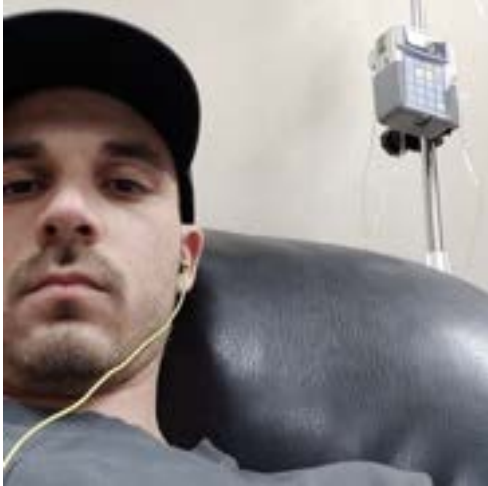
## Meet Matt, an advocate for transparent and effective communication

Have you had a chance to admire the stunning new graphics in the latest editions of the ACP newsletter email? This month, we'd like to introduce you to the creative mind behind them. Matt Allen enjoys doing freelance graphic design work, which is one of the many roles he takes on at the Accelerated Cure Project. Take a moment to get to know him!

Matt is originally from, and currently resides in Southern California. He took business classes at a local community college until 2010, when his schedule became overwhelming due to his MS diagnosis. He currently does freelance graphic design and writing. In his words, "Freelance work gives me the most flexible schedule for the ups and downs of MS." In his free time, he likes to read, watch old movies, and he enjoys gardening.



"I try to keep things calm and simple in life. I love music and definitely spend more time wearing headphones than I spend without them."



“I’ve been on [Copaxone](#), [Rebif](#), [Tysabri](#), [Aubagio](#), [Zinbryta](#), [Lemtrada](#), [Ocrevus](#), and finally [Kesipmta](#). I guess you could say we were having a hard time getting my MS under control.”

Matt was diagnosed with MS in 2010, when he was 20 years old. He shares, “Before that my life was very different. I was big into art (specifically drawing, a little sculpting, a little painting, and of course writing) and I really enjoyed being outside whether that meant camping, hiking, or dirt biking.... My very first MS symptom was waking up with numbness in one foot and pins and needles in the other. Over the next couple of weeks both of those symptoms spread up to my shoulder blades. Next was my vision (optic neuritis), balance, weakness, foot drop, and so many other little symptoms... The most prominent part of MS in my daily life now is fatigue which is, in my opinion, hands down the most debilitating MS symptom. Between that and my balance I’m obviously not as active as I once was.”

Immediately after his MS diagnosis, Matt started blogging to track his progress and meet others in similar circumstances. Through that and social media, he has connected with many other people around the world who are also living with this disease. Both have deepened his understanding of the unique experiences and challenges that people with MS face, as well as the strong sense of mutual support within the MS community.

“I quickly decided that I was in a unique position to try to turn my circumstances into something positive that could help others.”



Matt quickly saw how social media helps people with MS and similar conditions connect and build a sense of community. He leverages this awareness to oversee iConquerMS’s social media presence and produce its content.



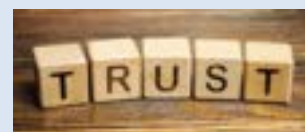
Matt has been an active participant at the [iConquerMS Leadership Summit](#) and plays a lead role in the Next Steps Committee (NSC). The NSC meets every month to discuss how the initiative will continue to advance the work done at the Leadership Summit. In Matt’s words, “Most of the people that are part of the NSC, such as myself, are living with MS and therefore have unique insights and experiences to bring to the table when working to constantly improve iConquerMS and its value to the MS community. As this committee has an ongoing goal of trying to improve and grow this initiative, I envision it growing in size allowing more people to focus on more of the little things brought up at the Leadership Summit that we may not otherwise have the manpower to address.”

“My favorite part of participating in the Leadership Summit is getting together and brainstorming with a huge group of people from so many different locations, backgrounds, experiences and areas of expertise. I love the problem-solving process because it can often involve a certain degree of creativity. The diversity of people attending the Leadership Summit offers a rich assortment of unique ideas for ways to possibly solve problems and overcome challenges that the MS community and iConquerMS may be facing.”



Matt also volunteers as a member of the Engagement Committee, where he contributes his expertise to create and implement engagement strategies aimed at growing the iConquerMS community and enhancing collaboration with its members. The Next Steps Committee established a subgroup of the Engagement Committee, known as the Building Trust Committee, which Matt co-leads. This group focuses on identifying potential trust issues within the MS community concerning medical research. Their goal is to provide accurate information about the research process, addressing any doubts people may harbor and increasing the transparency of iConquerMS.

“Ensuring a trustworthy environment is a priority for me because I personally understand how easy it is to be untrusting of medical research and how hard it can be to shed previously held misconceptions. By actively promoting transparency and information about the research process, we're striving to strengthen people’s trust in iConquerMS.



**What's your favorite role at ACP?**

“My favorite “role” would probably be developing content for social media because I enjoy working on and trying to improve our messaging/communication in ways that people can easily connect with. Plus, trying to fit a message into a tweet with a 280-character limit usually requires a bit of ‘problem-solving’ which, again, I really enjoy.”



**What about ACP's mission inspires you the most?**

“To me, the most inspiring part of ACP's and iConquerMS's mission is how it enables the research process to start with individuals actually living with MS rather than a random researcher whose priorities may not align with those of the MS community. I see ACP and iConquerMS as positive forces working to advance MS research for all the right reasons.”



**What about iConquerMS makes it such a powerful tool for advancing MS research?**

I wouldn't say that any one feature makes iConquerMS a powerful tool, I would say the very concept of putting people living with MS front and center in the research process is what makes iConquerMS such a powerfully unique tool.



We appreciate Matt's commitment to keeping the iConquerMS community informed and engaged through his work in social



media, and his role in shaping strategic initiatives will help ensure that the voices of those affected by MS are heard and valued in MS research. Matt's expertise and insights greatly enhance our mission and we look forward to what we will accomplish as we collaborate with people living with MS, researchers, healthcare providers, and other advocacy organizations (among others) and work together to accelerate MS research toward better ways to diagnose, treat and eventually cure the disease. Stay tuned!

**REASONS TO JOIN iConquerMS**  
**IF YOU ARE LIVING WITH MS**

**Reason 1:** As someone living with MS, you know the disease better than anyone.  
When you take surveys about your daily MS experiences and symptoms, you help to create a key resource for researchers.

**Reason 2:** Your voice matters.  
When you suggest research topics it strengthens the connection between people living with MS and the research community

**Reason 3:** It's secure & easy to participate.  
When you contribute health data, we will take every reasonable step to protect your identity and privacy.

**Reason 4:** You will become part of a passionate MS community  
People who have MS, MS caregivers, and those who simply care about this illness.

Learn more or join today at [iConquerMS.org](http://iConquerMS.org) **iConquerMS™**

## Looking Back at 2023

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 2023. 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?**



The **Keto Diet** is a popular way to lose weight without exercising. [Discover](#) what researchers have learned about its potential benefit for people with MS.



[Read](#) about 8 **anti-inflammatory foods**, with evidence supporting why they may be worth exploring for people with MS.

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



[Learn more](#) about **depression**, including some effective therapies that can help.



[Unravel](#) **MS fatigue** and discover some possible ways to cope with it.

Are you an MS caregiver? These articles are for you!



See what [studies](#) have shown about many aspects of being a **caregiver** and pick up some tips to make this job easier.



Peruse **ACP's ongoing activities** aimed at relieving caregiver burden and increasing the voice of this important population in research!

Showcasing individuals that play vital roles in ACP's initiatives!



**Meet Jordan Caines**, the Program Manager of the iConquerMS RIDE Council!



**Introducing Rob Sarles**, an advocate for inclusion!



**Get to know Matt Allen**, a supporter of transparent and effective communication!

Researchers are making headway toward understanding many facets of MS.



Does **head injury** increase the risk of MS? [See](#) what the research says.



Many **personal traits and aspects of daily life** can affect the course and outcome of MS. [Discover](#) what they are!

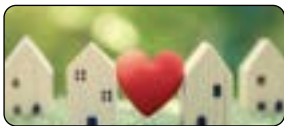


[Catch up](#) on what investigators say about **treatments for primary progressive MS**.



There is [evidence](#) that **spiritual practices** help people with MS.

Looking for ways to brighten up daily living?



[Click here](#) for some ideas on how to make your **home more MS-friendly!**



Do you like **good music and fellowship**? [This article](#) is for you!



Does a **Cape Cod vacation** in a fully accessible town house sound heavenly? [SMILE Mass](#) can help!



## Interested in what's happening at ACP?



[Read about](#) the exciting ideas for deepening our impact that were discussed at last year's **Leadership Summit!**



Looking for iConquerMS study results? [Check out](#) the **Research Projects page** on our website!



The iConquerMS community now includes children, adolescents and their family members! [Read about](#) the **iConquerMS Kids & Teens** program.



The **ACP Repository** is a powerful tool in the next generation of MS research. [Read more...](#)



iConquerMS members will soon play a key role [evaluating](#) an **online program** that is used to treat MS fatigue in Germany.

According to Robert McBurney, ACP's Chief Research Officer, "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 coming 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!



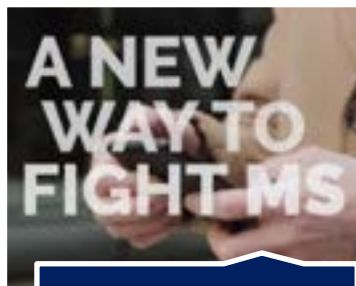
## December 2023 Donor's Corner

We know you want to find a cure for MS. When you [donate](#) to ACP, you are supporting global research directly focused on doing just that – curing MS for good.

**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

**We don't fund research. We fuel it.** When you [give](#) to ACP, you're not just supporting one study. You are helping researchers around the world conduct groundbreaking studies that get us closer to a cure.

MS affects kids, older people, and historically marginalized people in different ways. Thanks to ACP's work to promote inclusive research engagement, the evidence generated by research studies no longer leaves these groups behind.

Your [donation](#) to ACP helps us provide researchers with the data they need to study different populations and develop a cure that will help everyone with this disease.



**The face of MS is  
changing**





At ACP, we're committed to accelerating the essential research needed to find a cure for MS – for you, for your loved ones, for all affected by MS. As a member of the ACP family, we know you are too.

Please consider making a [donation](#) today! Together, we are working to make this important research possible.

## December 2023 iConquerMS Spotlight

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 the past year.



In 2023, the iConquerMS network has grown to over 8,500 adults living with both relapsing remitting and progressive forms of MS.

## Advancing participant-driven research



iConquerMS members are shaping MS research through the **Our Questions Have Power** program. Through this initiative, participants can suggest research questions and vote on others' suggestions. These questions are shared with MS-affected individuals, researchers, healthcare professionals, advocates and funders. Together we are working to launch research aimed at answering them.

## Expanding and enriching the iConquerMS network



iConquerMS welcomes children, adolescents and their family members through the **iConquerMS Kids & Teens program**! Support for pediatric MS within the network was 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. **iConquerMS Caregivers** gives carers the opportunity to participate in the design and conduct of research. We are also working to develop a **Care Partner Protocol** to provide access to resources to address many of the situations caregivers face.

## 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!

## Working to diversify MS research



◆ **Working to ensure MS research benefits one and all.** The **RIDE Council** is addressing historical underrepresentation in research. Clinical studies should include everyone, regardless of race, ethnicity, orientation, or economic status. They've crafted this message into **flyers** to amplify it and get more people involved. This grassroots movement could lead to improved healthcare and quality of life for everyone affected by MS!

## Investigating topics that matter to the MS community



◆ **Shedding light on patient support programs.** iConquerMS conducted a survey to understand the usage of support programs by people with MS. We are analyzing these data and plan to share the findings with the sponsor, and are exploring ways to share the results more widely.



**How does MS affect different races and ethnicities?** iConquerMS members completed a survey about their healthcare journeys, including their diagnosis, treatment choices, discussions about research and any instances of healthcare-related discrimination they encountered. The **results** have been incorporated in an online educational program for medical professionals, ensuring they stay well-informed about these issues.



**Learning more about treatment effects.** Some people report that with some MS medications their symptoms worsen as they approach their next scheduled dose, but after receiving the dose, they feel better. We're about to launch a study in collaboration with Novartis for people taking Kesimpta and Ocrevus to find out what their symptoms are like during treatment and whether or not they experience this effect.





◆ **Working together to defeat COVID-19!** The **COVER-MS study** shows the frequency of vaccination reactions in people with MS is similar to that reported in the COVID-19 vaccine clinical trials. A **COVER-MS sub-study** is now exploring the effectiveness of COVID-19 vaccines at preventing the virus in people with MS by measuring antibody response. Analysis of these data is underway, stand by for the results!



**The MS Diagnosis Experience.** A recent study, hosted by the iConquerMS network, found that about half of all individuals with MS conceal their diagnosis from others because they fear disclosure would have negative consequences. Results show a number of factors make this decision more likely. Are you curious what they are? [Read more...](#)



**Collaborating to conquer MS fatigue!** iConquerMS members will soon have the opportunity to help evaluate the effectiveness of a new, non-drug treatment for MS fatigue. **ELEVIDA** is used to treat MS fatigue in Germany. If the results of this upcoming clinical trial are favorable, it could be FDA approved and covered by insurance in the United States. This would be a significant breakthrough for everyone affected by MS. Stay tuned!

[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 2024!



## 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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### Beating MS Fatigue!

Next year, iConquerMS will be launching a new study of an online therapy to treat MS fatigue. This study, called CAFE-MS (Confirmatory Trial for Alleviating Fatigue with ELEVIDA in MS), will evaluate how well a cognitive behavioral therapy program accessed over the Internet works to treat MS fatigue.

Your input will help us plan this study so that it meets the needs of the MS community. Please take a few minutes to read a [short summary](#) of the trial and then answer the 4-5 questions that follow. You can also find more information about CAFE-MS in our [October newsletter](#).

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To improve the health and care of women with Multiple Sclerosis, NYU Langone Health is doing an anonymous survey study to explore how women with Multiple Sclerosis may want to learn about sexual health related to their diagnosis. The intention is to use the information obtained in this survey to create educational materials to teach women about sexual health in Multiple Sclerosis.

Taking part in the study is 100% voluntary. Choosing to take part in this study will not affiliate you with NYU Langone Health in any way. The survey will take about 15-20 minute to complete.

If you are interested in participating, please scan the QR code with your phone or follow the link to access the survey. Please complete the survey in its entirety.

Sincerely,

Meredith Wasserman, MD MS  
Division of Female Pelvic Medicine and Reconstructive Surgery  
Department of Urology  
NYU Langone Health

**Anonymous Survey of patient education preferences regarding sexual health in women with Multiple Sclerosis**

<https://redcap.link/m7ns6by2>





**COLORADO STATE UNIVERSITY**

## **Hormonal Stages of Life and MS**

Researchers at Colorado State University are conducting a survey study that aims to determine whether distinct hormonal stages of life (menstrual cycle, hormonal contraception, pregnancy, postpartum, post-menopause) influence disease symptomology, physical function, and the capacity to perform activities of daily living in women living with MS.

Participation involves filling out an online questionnaire that will take approximately 10-15 minutes to complete. This is an anonymous questionnaire in which no personally identifiable information will be collected.

### **Inclusion Criteria:**

- Female sex assigned at birth.
- A diagnosis of MS.
- Aged 18 years or older.

**Survey Link:** [A Survey on the Influence of Hormonal Stages of Life on Multiple Sclerosis Symptomology and Physical Function](#)

If you have any questions about the research, please contact Kristin Johnson, Postdoctoral Research Fellow, at [kristin.johnson@colostate.edu](mailto:kristin.johnson@colostate.edu) or Brett Fling, Associate Professor and Director of the Sensorimotor Neuroimaging Lab, at [brett.fling@colostate.edu](mailto:brett.fling@colostate.edu).

For information about the impact of MS in women please see:  
<https://www.nationalmssociety.org/What-is-MS/Who-Gets-MS/Women-with-MS>

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

# Research Opportunity

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

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

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

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

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

## Initial eligibility

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

**For More Information:  
Contact the Project Coordinator**

**Key Words: BIPAMS-Cognition**

**Phone: (833) 329-1441**

**Email: [bipamscognition@uic.edu](mailto:bipamscognition@uic.edu)**

**Website:**

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







# RESEARCH OPPORTUNITY AT HOME EXERCISE STUDY

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
- Complete an evidence-based, tailored exercise program in your home or community



## 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.®



**The Wait is Over!**  
**New REAL MS Surveys are HERE!**



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

Your health information is important even if you think things haven't changed much in the last few months. Thanks for completing your REAL MS surveys!

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

Thank you for your participation! Your data – especially your REAL MS data – has **power!**

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**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.