

April 2023 Newsletter

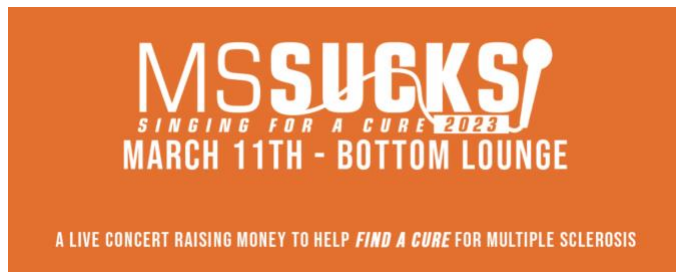


Do You Like Good Music and Fellowship? This is for you...

ACP is committed to accelerating research to cure MS and to enable people affected by the disease to live their best lives.

Volunteers help us in our mission in a variety of ways. Kaustubh Pandav (“Stubhy”) is the lead singer of [Lucky Boys](#)

[Confusion](#), an American rock band from Chicago. He and his colleagues in the music industry recently donated their time and talents to raise funds to enable the work that we do through the MS Sucks: Singing for a Cure concert. Read more about Stubhy’s MS journey and the success of this sold-out event!



Music plays a big role in Stubhy’s life, it is one of his greatest passions. In his words, “I was a poet before I realized I had a gift for melody. It’s my release, it’s my outlet, it’s my go-to when everything else is failing.” At the end of 2015, Stubhy noticed he was having difficulty walking, his leg started dragging and hitching. He underwent extensive testing and tried a number of remedies over the next two years, including chiropractors, massage and physical therapy, to no avail.



Eventually, Stubby's neurologist ordered an MRI which showed lesions in his brain and spinal cord. On Black Friday 2018, Stubby was diagnosed with MS. His neurologist prescribed [Ocrevus](#), but Stubby's insurance company declined coverage, wanting him to try other disease modifying therapies that are less expensive. He immediately went into action, looking for other solutions and was eventually approved for Ocrevus treatment through the [Genentech Foundation](#). He shares, "I didn't have the chance to be sad because I had to get going. I had to work at getting myself better, my wife was three months pregnant. Too many people in my situation with the insurance company would have folded their arms and said, 'OK, this is the hand I've been dealt.' There are other resources out there. There are other ways to do it. You just have to fight because nobody else is going to fight for you if you don't fight for yourself... Luckily everything worked out, as much as it works out when you have MS. I'm very fortunate and have had great results."



After doing extensive research into possible beneficiaries, Stubby decided to give the proceeds of the concert to ACP. In his words, "I wanted a charity that is focused on research and cures... ACP is a patient-founded organization fully focused on raising funds for a cure."

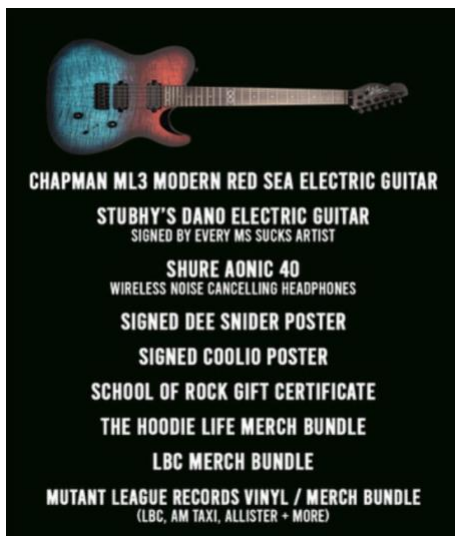
Stubby wanted to give back to the MS community. In December 2019, he organized the first MS Sucks: Singing for a Cure charity concert, raising over \$30,000 for MS research. He shares, "It makes getting through this a little bit better knowing that you're doing something that does some good for people. My dad was a real big philanthropist in his own right. He was really big into charity and donations, giving of his time more than anything else. I think I just picked up on that growing up, I just didn't have a cause until now."

The pandemic delayed plans for an annual concert, but round two was worth the wait! MS Sucks 2023 was held on Saturday, March 11th at the [Bottom Lounge](#) in Chicago. Over 700 people enjoyed this sold-out show featuring performances by Lucky Boys Confusion, [The Waiting Game](#), Josh Caterer from the [Smoking Popes](#), Tom Higgenson from the [Plain White T's](#) and Art Alexakis from [Everclear](#).



ACP staffer, Lindsey Santiago, and her son, Max, with Tom Higgenson from the plain White T's

This year's concert raised another impressive total of over \$43,000. For Stubhy, it was successful in other ways, too. He states, "Music is the background of the event. It's more about people coming together to raise awareness and raise some money for a cure... People came up to me and said they were at the show because what I brought up made them realize they probably had something going on, too. I got a couple of people to go to neurologists. Nothing makes me feel happier than that, early detection is important. We raise thousands of dollars and sell hundreds of tickets, but the thing that makes me the proudest and makes me choke up a little bit is making a difference in people's lives."



MS Sucks 2023 Raffle Items

The concert featured a raffle that raised over \$7,300. Raffle prizes included two electric guitars (one of which was signed by every performing artist at the concert), signed [Dee Snider](#) and [Coolio](#) posters, a [School of Rock](#) gift certificate, and merchandise from Lucky Boys Confusion, [The Hoodie Life](#) and [Mutant League Records](#). In addition, MS Sucks t-shirts and sweatshirts were available for purchase during the show. All proceeds will support ACP's work to accelerate MS research to improve the health, healthcare, and quality of life for those affected by the disease.

The concert reached the hearts of many people in the MS community. Those in attendance felt the love and support that was the spirit of the event. According to Lindsey Santiago, Development Associate at ACP, "It was an amazing show, from the acts, to the people attending, to the entire MS Sucks team. Seeing how many people came out to support an amazing cause, Stubhy and Art's



With ACP staffer, Lindsey Santiago, at the Bottom Lounge

performances were incredible, also meeting new people and talking to them backstage about MS.”

The MS Sucks concert had a tremendous amount of support behind the scenes. [Alex Zarek](#) and Jennifer Kurz served as photographers throughout the event. Alex was also the chief graphic designer behind the MS Sucks merchandise. The concert was a resounding success thanks to the efforts of many other volunteers, including Sam McHale, Jenna Michals, Elijah Nelson and Dan Volz. We’d also like to thank [Bristol Myers Squibb](#), [MedRhythms](#) and the School of Rock for their generosity as sponsors, the Bottom Lounge for providing the venue for the event, [James VanOsdol](#) (JVO) for hosting the show and [Mer Mansuria](#) for providing a full lunch backstage for the crew.

We are grateful to all who helped make the concert as powerful as it was, both named and unnamed.

♥thank you volunteers♥

Funds raised from events like these help us to continue our work to improve diagnosis, optimize treatment, and find a cure for MS. If you missed MS Sucks: Singing for a Cure 2023 and would like to make a [donation](#), it’s not too late! If you have a favorite activity that friends and family members enjoy doing or talents you would like to share, hosting a fundraiser is a great way to reach out to your community, raise funds for ACP and have fun while doing it. For more information on hosting your own fundraiser, contact Lindsey Santiago at lsantiago@acceleratedcure.org or (781) 487-0013.



How to Lift Your Spirits in Dark Times

WHAT IS DEPRESSION?

Everyone feels sad or down at times, but clinical depression is different. It is a constant feeling of sadness or low mood that lasts for two weeks or more, often interfering with everyday activities. Depression can be mild, moderate or severe, depending on how much it affects your life and you can experience different levels of depression at different times. It can make you lose pleasure in things that were once enjoyable. Some people even have thoughts of suicide. If this is the case, the [988 Suicide & Crisis Lifeline](#) is there to help.

People affected by MS are at the center of everything we do at ACP, including the newsletter.

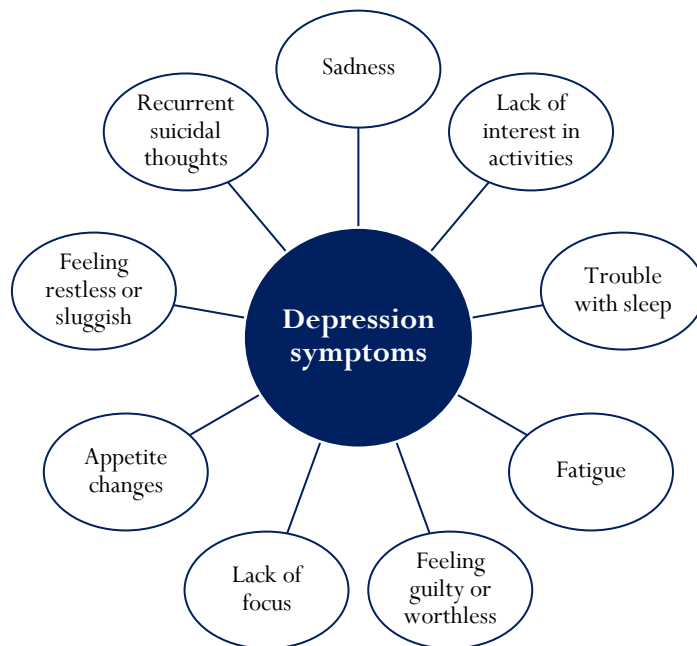
Each month we include a [survey](#) asking for feedback and content

ideas for future issues. This month we focus on a topic that many of our readers have asked about – depression and MS.



Depression is one of the most common symptoms of MS. [Research](#) shows it occurs in up to half of people with MS, which is two to three times higher than the general population. The effects of depression can be devastating. It can make even simple activities a challenge. Many of its symptoms are invisible, which often leads to misunderstandings. Those struggling with depression frequently turn inward, withdraw from family and friends, and stop participating in social activities. Loss of libido is a chief complaint among individuals experiencing depression, which may also damage relationships. There is [evidence](#) that depression can impact a person's ability to work. For a depressed individual with MS, a loss of employment and insurance benefits can have a devastating impact. An individual living with both MS and depression may not be inclined or able to follow his or her treatment plan, which could also have detrimental effects in the long run.

Depression symptoms are complex and vary widely from person to person. Several are also symptoms of MS, such as fatigue, insomnia and cognitive difficulties. These similarities make diagnosing depression challenging in someone with MS. The [screening tests](#) for depression are typically in the form of a questionnaire. These instruments can also be used in follow up to assess whether symptoms change with treatment.



There are several different types of depression:

<p><u>Major Depression</u> – Distinguished by at least 5 of the above symptoms over a two-week period.</p>
<p><u>Persistent Depressive Disorder (Dysthymia)</u> - Similar symptoms to major depression, but they are more insidious and less severe, often lasting for at least two years.</p>
<p><u>Bipolar Disorder (Manic-Depressive Disorder)</u> – Characterized by extreme mood swings. Manic symptoms are typically short-lived and followed by a period of depression.</p>
<p><u>Seasonal Affective Disorder</u> - Related to the change in seasons. It usually occurs in the fall and winter, when days are shorter.</p>

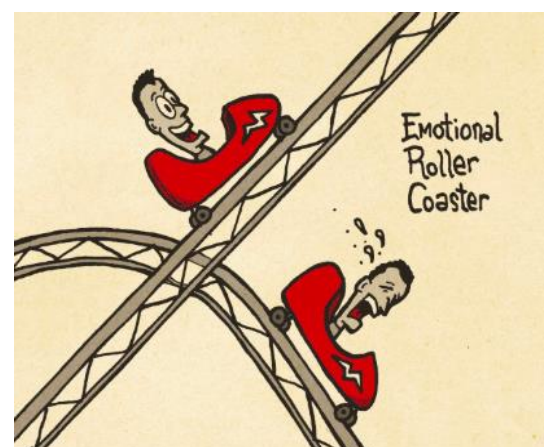
Two types of depression are influenced by reproductive hormones and primarily occur in women:

Premenstrual Dysphoric Disorder (PMDD) - A severe form of premenstrual syndrome that causes extreme, disruptive mood swings. Symptoms usually begin shortly after ovulation and end once menstruation starts.

Postpartum Depression - Occurs during pregnancy or within one year after birth

While depression can potentially occur in any person with MS at any point in the course of the disease, a number of factors increase its likelihood. It is nearly twice as likely to occur in women than men. Many aspects of living with MS, and the disease itself, have the potential to cause depression. One [imaging study](#) suggests it may be the result of nerve damage in areas of the brain that are associated with mood. [Researchers](#) at UCSF conclude that the abnormal immune response that occurs in MS may, in fact, cause depressive symptoms. Some of the medications used to treat MS and manage its symptoms may be linked to depression. Steroids are often prescribed during exacerbations, a time when people with MS are already vulnerable to depressive symptoms. Steroids often cause a short term “high” when first given followed by an emotional plunge once the medication is stopped. Depression is a suspected side effect of [interferon beta treatments](#) for MS, although the [evidence](#) to support this is mixed. Other illnesses can contribute to depression as well, such as thyroid issues, changes in blood sugar levels, and urinary tract or other infections. Therefore, it is important for anyone struggling with depression to have a physical examination and laboratory testing to rule out any underlying (and treatable) physical cause.

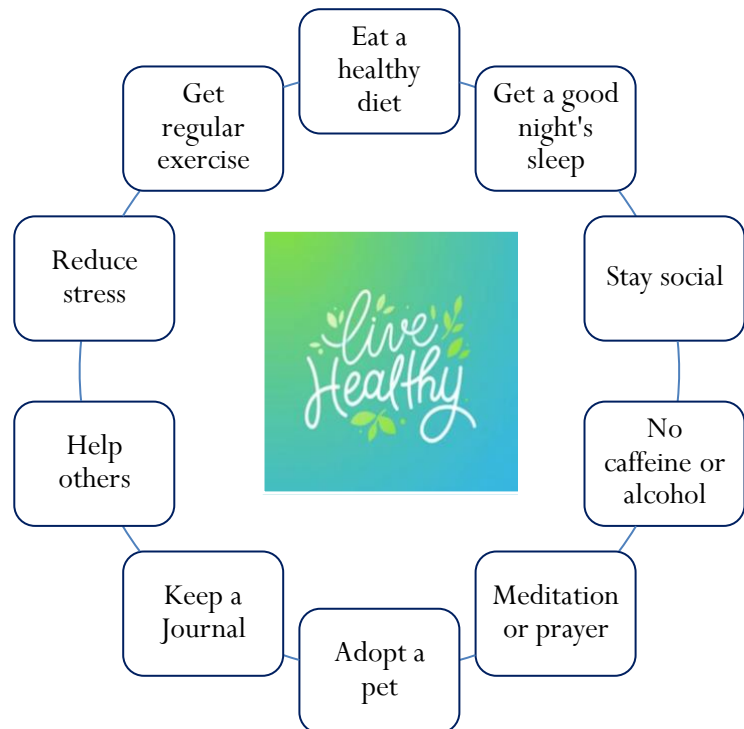
[Researchers](#) at Case Western Reserve University identified several risk factors for depression in MS using samples and data from the ACP Repository. They include genetic factors, having a mother with a history of depression, obesity, hypertension, mononucleosis, and obstructive pulmonary disease.





Depression is one of the most treatable of all MS symptoms. The most common medications used are [selective serotonin reuptake inhibitors](#) (SSRIs), [serotonin and norepinephrine reuptake inhibitors](#) (SNRIs) and [tricyclic antidepressants](#). It's important to be aware that antidepressants can take six to eight weeks to reach their full effect. As mentioned in our [February 2019 newsletter](#), dietary supplements such as St. John's wort and ginkgo biloba are thought to help with symptoms of depression. [Research](#) suggests that fish oil supplementation can also be beneficial in this regard. Anyone considering dietary supplements should first consult his or her physician as these can cause serious side effects and/or interactions with other medications.

Healthy living can be very helpful in coping with depression. Some useful strategies include:



[Studies](#) show the most successful treatment plan for depression is to seek counseling in conjunction with a prescribed drug therapy. A number of professionals are specifically trained to provide objective insight and coping skills to help manage the symptoms of depression, including a psychiatrist, psychologist, social worker, or a counselor. A variety of therapeutic approaches may be used during the counseling process, such as [talk therapy](#) and [behavioral therapy](#). Counseling sessions may be conducted individually, with couples, families, or larger groups. Some less traditional therapy options also include [phone therapy](#) and [online therapy](#). These options may be attractive to those who are home bound or otherwise unable to attend a counseling session.

The National MS Society's [MS Navigator program](#) provides people living with MS with the information, resources and support they need to combat depression and other challenges in MS.

Despite all of the devastating implications of depression, it is often ignored, and as a result, under-treated. While depression is common in people with MS, it is not universal and shouldn't be considered normal or expected. A common misconception is that depression can be overcome by willpower or religious belief alone, when, in fact, it is an illness that requires time, attention and treatment. Individuals with MS and their families should pay attention to symptoms of depression and notify their health care provider should any arise. There are effective therapies that can help dispel the gloom and return one to a happier, more peaceful place.



April 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

This month, we're highlighting how your generosity enables ACP to facilitate research that can positively impact people with MS through the ACP Repository.

[Researchers](#) at Case Western Reserve University identified several risk factors for depression in MS using samples and data from over 800 ACP



Repository participants. They identified several non-genetic risk factors, including having a mother with a history of depression, obesity, hypertension, mononucleosis, and obstructive pulmonary disease.

This study also identified genetic factors that may influence whether or not an individual with MS will develop depression at some point in the course of their disease. These genetic factors can easily be determined at MS onset and may potentially be used to identify those at high risk for depression.

The ACP Repository has been an invaluable resource for this and more than one hundred other studies. These data will be shared with and built upon by other MS researchers, advancing our understanding of the cause and effect of MS in the lives of those living with the disease. Advances such as these bring us closer to better treatments and a cure.

[Join](#) our team and consider making a [donation](#) today! Together, we are working to improve the health and quality of life for everyone affected by MS.



April 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.

iConquerMS Spotlight

COVER-MS Update

How effective are COVID-19 vaccines in people with MS?

[iConquerMS](#) is gathering important information about COVID-19 vaccines and how they work in people affected by MS. The [COVER-MS study](#) currently has over 1,600 participants. This [real-time data display](#) summarizes the information they have provided to date. Overall, [results](#) show the frequency of vaccination reactions in people with MS is similar to that reported in the COVID-19 vaccine clinical trials.



Want to learn more about what we've learned from COVER-MS so far?



See an overview of
COVER-MS results



"COVID-19 Vaccine Safety:
A Study from iConquerMS Data"



Featuring
Farren B.S. Briggs, Ph.D., Sc.M.
Assistant Professor, School of Medicine,
Case Western Reserve University

When:

Watch Chat with Chat,
Episode 4

**BUT WAIT
THERE'S
MORE!!**

Through a partnership with Quest Diagnostics and the National MS Society, we've recently launched a COVER-MS [sub-study](#) looking at the effectiveness of COVID-19 vaccines at preventing the virus in people with MS. 300 COVER-MS participants will donate blood every 6 months for the next 2 years. These samples will be analyzed to determine how MS drugs and other factors affect the immune response (antibody levels) to COVID-19. We are currently inviting participants to return for a second blood draw and have been able to provide them with antibody results from round one. Analysis of these data is underway, stay tuned for the results!

COVER-MS is open to anyone who has received a COVID-19 vaccine or plans to receive one. To join the study, [log in](#) to your iConquerMS account. Not already a member of iConquerMS? Please consider [joining](#) today! Thanks for your help in conquering COVID-19!

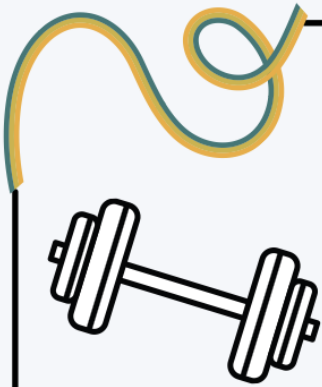


EVENTS



The Consortium of Multiple Sclerosis Centers (CMSC) is holding its [annual meeting](#) in Aurora, CO on May 31 – June 3, 2023. A few members of the ACP team and some people with MS who are involved with iConquerMS plan to attend. If you are in the area and would like to meet with us, we would love to see you there! Please [email](#) to make arrangements.

RESEARCH OPPORTUNITIES



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

<https://projectteams.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.®



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!



**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.