

# October 2022 Newsletter



## MS and Anxiety

Everyone feels anxious at some point, but this emotion is usually short-lived and doesn't affect daily activities. Living with an unpredictable, progressive disease like MS often adds to one's anxiety level. A common fear that individuals with MS share is about the future and how they might be affected by increasing levels of disability. In

addition, MS is associated with inflammation in the brain, which has been [shown](#) to trigger anxiety and depression in those living with the disease. Some of the medications used to treat MS, such as corticosteroids, can have significant effects on the emotions. The symptoms of MS can also be triggers for those that already have anxiety, creating an emotional environment that makes apprehension far more likely and severe.



Anxiety disorders are conditions in which anxiety doesn't go away. They often worsen over time and the resulting stress can interfere with daily activities and personal relationships. There are five major types of anxiety disorders:

## Types of Anxiety Disorders

**Generalized Anxiety Disorder** - Chronic anxiety, about a wide range of situations and issues, rather than one specific event, often without provocation.

**Obsessive-Compulsive Disorder** - Recurrent, unwanted thoughts and/or repetitive behaviors that don't help, but only make anxiety worse.

**Panic Disorder** - Unexpected and repeated episodes of intense fear that occur without warning and cause physical symptoms like chest pain, sweating or shortness of breath.

**Post-Traumatic Stress Disorder** - Anxiety related to a traumatic experience that has occurred in the past. If left untreated, it can persist for many years after the event.

**Social Phobia** - An intense, persistent fear of being watched and judged by others in social settings. These feelings can affect work, school and other daily activities.

According to the [Anxiety & Depression Association of America](#), anxiety disorders are the most common mental illness in the United States, affecting approximately 19.1% of the population. A number of studies have looked at their prevalence in people with MS. [Canadian researchers](#) concluded that 35.7% of people with MS have some kind of an anxiety disorder, with generalized anxiety disorder (18.6%), panic disorder (10%), and obsessive compulsive disorder (8.6%) being the most common. Data showed the risk factors for anxiety were being female, a co-morbid diagnosis of depression, and limited social support. Another [study](#) from Canada found the prevalence of anxiety in people with MS was nearly 30.0%. Results showed that low education increased the odds of anxiety and affected participants reported anxiety substantially reduced their quality of life. [Investigators](#) in Australia followed 198 people with MS for two and a half years. They compared the prevalence of anxiety (44.5%), depression (18.5%) and fatigue (53.7%). Data showed these three symptoms are common in people with MS and tend to cluster together. Interestingly, the prevalence of anxiety decreased by 8.1% each year the researchers observed study participants and this



effect was more pronounced in women than men. Investigators suggest this may be due to participants having a good support system, effective MS treatment, acceptance and positive lifestyle changes following their MS diagnosis.



Anxiety is caused by the body’s [“fight-or-flight”](#) response. This is an automatic physiological reaction that enables one to respond to perceived danger or threats. When a person feels fearful or stressed, their body produces a hormone called [adrenaline](#) and this causes a myriad of both physical and psychological symptoms. Interestingly, many of the physical symptoms of anxiety are similar to those seen in

MS. An adrenaline rush can be very useful, it prepares an individual for immediate action when threatened by danger. However, if this heightened state of alertness continues for too long (which is the case with anxiety disorders), it can affect one’s health.

### Anxiety symptoms

Physical symptoms like MS symptoms:	Other physical symptoms:	Psychological symptoms:
<ul style="list-style-type: none"><li>• Fatigue</li><li>• Feeling faint or dizzy</li><li>• Disrupted sleep</li><li>• Bladder and bowel dysfunction</li><li>• Numbness or tingling</li><li>• Nausea</li><li>• Ringing in the ears</li><li>• Tense or trembling muscles</li></ul>	<ul style="list-style-type: none"><li>• Pounding heart</li><li>• Breathing difficulties</li><li>• Dry mouth</li><li>• Excessive sweating</li><li>• Restlessness</li></ul>	<ul style="list-style-type: none"><li>• Chronic worry or guilt</li><li>• Racing thoughts</li><li>• Difficulty making decisions</li><li>• Feeling inadequate</li><li>• Inflexibility</li><li>• Hostility or anger toward others</li><li>• Repeating certain behaviors or thoughts</li></ul>

There are a number of ways to manage anxiety at home. Some people find it helpful to identify fears and write them down. This process can help break down larger problems that seem overwhelming into smaller, more manageable ones. It also helps “get them out of your head” and can make them less daunting. It’s important to be kind to yourself.

Often anxiety undermines confidence and makes you think negatively about yourself and your abilities. Try and remind yourself of your achievements and good qualities. Rather than worrying too much about tomorrow, try and live just one day at a time and focus on the present. Focused, deep breathing is another way to dispel unnecessary anxious thoughts. This slows the heart rate and promotes calmness. Something as simple as taking a bath can also be quite soothing. Practicing relaxation techniques like [meditation](#) and [mindfulness](#) may help with anxiety.

Healthy living goes a long way when it comes to easing anxiety. Getting a good night's sleep is not only a good idea in general, it may also help nerves not feel so frayed. Inactivity and a lack of mental stimulation may trigger or worsen anxiety. Keeping busy with projects and tasks is a way to prevent this. Exercise is beneficial in many ways, and also a great way of keeping spirits up and the mind active. Practicing [yoga](#) is a great way to combine exercise with mindfulness. [Research](#) shows that a wholesome diet is also



beneficial in this regard. Results show an association between less anxiety and eating more fruits and vegetables, omega-3 fatty acids and vitamin supplementation (for example, zinc, magnesium, selenium, probiotics, among others). Restricting calories and eating breakfast were shown to lower anxiety, too. Analysis revealed an association between higher levels of anxiety and a high-fat diet, eating sugar and refined carbohydrates, and “unhealthy” eating patterns like skipping meals. It’s important to avoid caffeine and alcohol as these are stimulants which can also precipitate or mimic symptoms of anxiety. People who smoke often say that it helps them cope with anxiety and stress. A [recent study](#) looked at how quitting smoking affected almost 8,000 people with MS. Results showed anxiety levels were actually higher in people who kept smoking compared to non-smokers and anxiety levels went down when people quit smoking.

Isolation and anxiety are not a good combination. Keeping in touch with other people can help ease apprehension in several ways. Being aware of issues and concerns in other people's lives can give you a sense of perspective on your own feelings. Other people may also have ideas and suggestions on how to deal with things that are worrying you. Even if people can offer no solutions, sharing a concern and



talking about how it makes you feel can be helpful. Some people consult with professionals (for example, a therapist, social worker or psychologist) to learn how to minimize the impact of anxiety and the negative thoughts and feelings it produces in their lives. These mental health professionals use several [types of therapy](#) to treat anxiety. Everyone's needs are different and finding the help that works best is important. Discussing any anxious thoughts or feelings with your doctor is a good start. He or she can help you find the best resources and make a referral to a mental health professional, if necessary. The National MS Society also provides a number of [emotional support services](#) and offers a [search tool](#) on their website that can help you find healthcare providers and other valuable resources that may be in your area.



If none of these things help, a number of medications are used to treat anxiety. [Selective serotonin reuptake inhibitors](#) (SSRIs), which were designed to treat depression, are also effective for many anxiety disorders. Examples include [sertraline](#) (Zoloft), [citalopram](#) (Celexa), [escitalopram](#) (Lexapro), and [fluoxetine](#) (Prozac). In addition, [serotonin-norepinephrine reuptake inhibitor](#) (SNRI) drugs like [venlafaxine](#) (Effexor) or [duloxetine hydrochloride](#) (Cymbalta) may be helpful. [Benzodiazepines](#), such as [diazepam](#) (Valium), are known for their calming properties and are used to treat anxiety on an as-needed basis. However, these drugs are habit forming and not intended for long-term use.

[Research](#) shows that anxiety disorders are common in people with MS, but they are frequently overlooked and undertreated. Emotional changes require treatment just like any of the physical symptoms of MS. Left untreated, they can affect functioning and quality of life. There are a number of approaches that can be used, including exercise, relaxation techniques, increased social support and medication. In some cases, a combination of these is most effective. There is [evidence](#) that identifying and treating anxiety early can make a big difference. It's important for anyone experiencing these troublesome symptoms to talk to their healthcare provider right away. With the right interventions, it's possible to get anxiety under control and minimize its impact on your life.

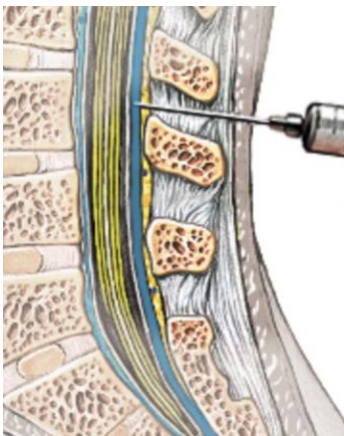


## Diagnosing MS – Lumbar Puncture

A spinal tap, or lumbar puncture, is a procedure that's done to collect a sample of cerebrospinal fluid (CSF). CSF is a clear, colorless liquid that surrounds the brain and spinal cord. Its primary function is to cushion the brain within the skull and serve as a shock absorber for the central nervous system. CSF also circulates nutrients to and removes waste products from the brain. In MS, damage to myelin causes certain types of proteins to be released into the spinal fluid. When these proteins are identified in the spinal fluid, but not in the blood, MS is thought to be a possible cause.



Lumbar puncture is used to help diagnose a number of conditions, including [meningitis](#), [encephalitis](#), bleeding in the brain, dementia, [myelitis](#), [leukemia](#) and autoimmune diseases like MS. Sometimes it is also used for treatments, for example, to inject local anesthetics, antibiotics or chemotherapy drugs into the CSF. This allows the drug to enter the nervous system directly, instead of through the bloodstream. When local anesthetics are given this way, it is called spinal anesthesia.

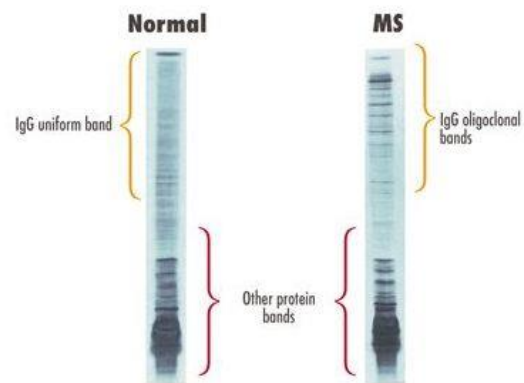


A spinal tap may be done on an outpatient basis or as part of a hospital stay. The procedure typically takes 15 – 30 minutes. A thin, hollow needle is inserted into the lower part of the lumbar spine, usually between the third and fourth, or the fourth and fifth, lumbar vertebrae. To make enough room for the needle, the vertebrae must be spread as far apart as possible. To accomplish this, the person undergoing the procedure is asked to lean forward and arch their back. This can be done while they are sitting down or lying on their side. The skin around the site of insertion is disinfected and numbed using a local anesthetic.

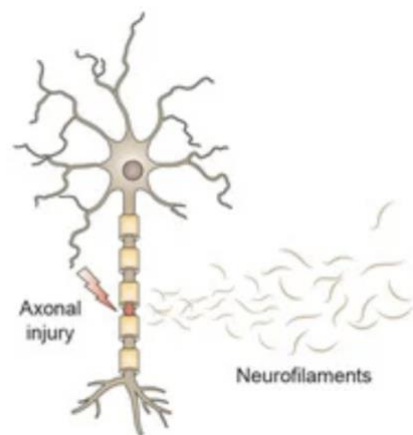
Once the needle is inserted between the two vertebrae, the doctor pushes it toward the spinal cord. In some cases, such as obese individuals or those with a spinal deformity, an ultrasound may be used as a guide. Once in place, the CSF trickles through the hollow needle into a sterile container. Approximately one tablespoon of the fluid is typically

collected. The needle is carefully removed and the site of insertion is covered with a bandage. Individuals undergoing a spinal tap often have blood drawn for testing, too.

CSF samples are sent to a lab for analysis and results are typically available two to three days after the procedure. The immune system produces [antibodies](#) to fight infection. In MS, antibodies cross the [blood-brain barrier](#) and attack the myelin that surrounds the nerves. As a result, the level of antibodies in the CSF of someone with MS is higher than normal. The test that shows the presence of antibodies is called [electrophoresis](#). A sample of CSF is placed on a gel and an electric current is applied to it. This causes antibodies of the same size to bunch together, forming visible “bands.” [Immunoglobulin G](#) (IgG) antibodies are the most common antibody in the body. They are important for fighting infections from bacteria and viruses. One IgG band (monoclonal) in the CSF is normal. Two or more IgG bands ([oligoclonal](#)) indicate inflammation in the central nervous system. A [recent study](#) shows that oligoclonal bands are found in the CSF of the vast majority of people with MS (over 95%) and are considered to be a “immunological hallmark of the disease.” It’s important to note that oligoclonal bands are present in other diseases, too.



There are a number of other CSF biomarkers for MS. For example, [research](#) shows over half of people with the disease have elevated white blood cells in their CSF. Other proteins resulting from the breakdown of myelin may also be present in the CSF of someone with MS. [Neurofilaments](#) are fragments of the structural support that normally surround the nerve axons. If neurofilaments are found in the CSF, this is evidence that the myelin has been damaged.



A doctor usually takes a thorough medical history and performs a physical exam prior to a lumbar puncture. It’s important to provide your healthcare provider with a complete list of medications as some may need to be stopped a few days prior to the procedure. For example, blood thinners like aspirin or warfarin should be stopped to prevent bleeding that

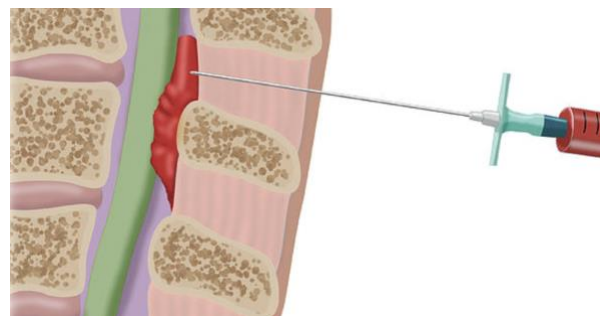
could damage the nerves around the site of needle insertion. Bloodwork to check for bleeding or clotting disorders may be necessary for the same reason. [Research](#) shows that performing a spinal tap in the presence of raised intracranial pressure is not advised. A physician may recommend a [CT scan](#) or [MRI](#) beforehand to check for causative factors like abnormal swelling in or around the brain.



Although lumbar puncture is considered safe, it does carry some risks. It should not be performed if the skin at the site of insertion is inflamed, intracranial pressure is too high, or there is an increased risk of bleeding. The administration of local anesthesia beforehand often stings and it isn't unusual to feel pressure in the lower back during the procedure. There are many nerves in the spinal canal and, if the needle touches one of them, a sudden, sharp pain may shoot down the leg and immediately go away. Burning or nerve twinges are also possible. Some people experience lower back pain after the test which is usually confined to where the needle penetrated. Other potential complications of a spinal tap include infection and bleeding, both of which are rare.

The most common side effect of a spinal tap is a severe headache. A [2020 study](#) shows that this is more likely in those who are younger and have a lower volume of CSF. This occurs because of a pressure drop in the CSF and can be due to the removal of the sample or a leak from an unclosed puncture site. The headache usually starts a day or two after the procedure and lasts anywhere from a few hours to a week or more. It is usually worse while standing or sitting, and can be accompanied nausea, vomiting or dizziness. To reduce the risk of headaches, it helps to lie flat for a few hours following a spinal tap and drink plenty of water. It's also a good idea to avoid intense exercise for a day or so afterward.

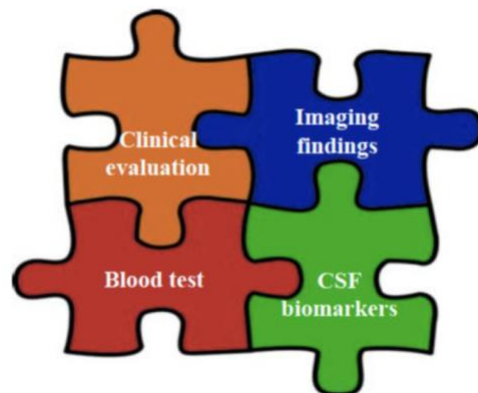
Most post-lumbar puncture headaches resolve on their own. They are best treated with bed rest, drinking fluids, and pain medications. [Research](#) shows that caffeine can also be helpful. In severe cases, a physician may perform a [blood patch](#). To apply a blood patch, a small volume of [autologous](#) blood is injected at the original puncture site. The blood restores the pressure in





the spinal cord and helps seal any leak that may still be there. Many people feel better right away, but it could take a day or two. Occasionally, a second blood patch is necessary.

It is important to note that a lumbar puncture by itself cannot confirm or exclude an MS diagnosis. A number of other diseases cause oligoclonal bands and other biomarkers of MS in the CSF. Approximately [5 to 10 percent](#) of people with confirmed MS have normal spinal tap results. In order to make an accurate [MS diagnosis](#), lumbar puncture should be used in combination with a complete medical history, neurological exam, [MRI](#) and other necessary tests.



## October 2022 iConquerMS Spotlight

[iConquerMS](#) members are part of a community that is making a difference! Read on to learn about the progress the initiative is enabling and how you can get involved! Not already an iConquerMS member? Please consider [joining](#) today!



### **Review the iConquerMS research portfolio – Learn more about the studies iConquerMS has made possible and the evidence being generated!**

The iConquerMS community has made many studies possible over the years, and now there's a convenient place to track their status and review the findings. On the

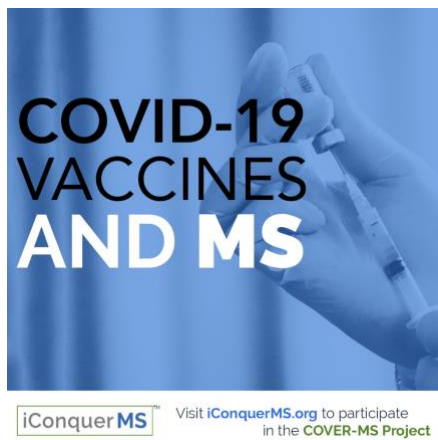


new [Research Projects](#) page, you can find summaries of studies that are completed or in progress. For studies that have published their results, links to those reports and presentations are provided for those who would like to learn more. We'll be posting additional summaries over time and would love to know what you think, so please [email us](#) with any feedback!

### **Learn about the latest COVER-MS developments**

One of the studies featured on the Research Projects page is the COVER-MS study of COVID-19 vaccinations in people with MS. The study team has already published data on the safety of these vaccines, and now we're exploring their effectiveness in preventing COVID-19. Through a partnership with Quest Diagnostics, blood samples donated by COVER-MS participants are being analyzed to determine how MS drugs and other factors affect the immune response to COVID-19. You can learn more

about this sub-study [here](#), and **enrollment is still open if you'd like to join**. Thanks to all COVER-MS participants for your help in the continued fight against COVID-19!



## Help people with MS succeed in the workplace

People with MS often have to leave the workforce before they're ready to, but it doesn't have to be this way. Our newest research survey is gathering information about work-related challenges and resources for people with MS. The results will be used to develop personalized tools that help people with MS make employment decisions and access resources to stay employed. **If you're currently employed or were employed in the past 5 years, we hope you will take this survey and share your valuable perspectives.** To participate, [log into your iConquerMS account](#), click "View and Complete My Research Surveys," and then click on the survey named "Employment Experiences and Resources." Participants will be entered into a gift card drawing. Thank you!



## Don't miss the Chat with Chat webinars!

Hosted by our research partner Chat Ngorsuraches from Auburn University, the Chat with Chat webinars are a great way to take a deeper dive into the research iConquerMS is supporting and conducting. Attendees are welcome to ask questions or just listen. To date, Chat has hosted 8 webinars (listed below) on a wide variety of topics.



In [Episode 1](#), Chat spoke about his own research to better understand how people living with MS value disease modifying therapies.

In [Episode 2](#), Chat spoke with Dr. Nina Bozinov about factors that affect quality of life for people with MS

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

In [Episode 4](#), Chat spoke with Farren Briggs PhD ScM, about COVID-19 vaccine safety.

In [Episode 5](#), Hollie spoke with Dr. Mitch Wallin about telemedicine and MS.

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. Icometrix surveyed the iConquerMS community about access to their own MRI files. This presentation summarized results from this survey.

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 hosted a conversation with Dr. Sarah Minden from Brigham and Women's Hospital about the use of complementary and alternative medicine (CAM) by network members.

Stay tuned to the iConquerMS [YouTube channel](#) for future episodes!



## October 2022 Research Spotlight

### EVENTS



Are you within driving distance of Burlington, Massachusetts?

The wearing of a facemask is requested *but solely at the discretion of each person attending*

**11:35am - Guest Speaker: Paul Pelland “Long Haul Paul” - MS Patient Advocate**

Listen to this compelling story about this motorcycles’ similarity to MS

→ Entering the World’s Toughest Motorcycle Competition on the most unreliable bike ever built is a lot like everyday life with MS. A painfully humorous and inspiring story of overcoming monumental challenges with ingenuity and sheer will power. - a 35 minute discussion + 5 mins of Q&A



**12:15pm – Guest Speaker: Cherie Binns, RN – MS Patient Advocate**

Patient Healthcare Liaison at MS FOCUS the Multiple Sclerosis Foundation. Works as Program Presenter at Multiple Sclerosis Foundation and Healthcare Advocate at MS Certified Nurse with Gerontology Degree. Board member with MS Views and News.

→Topic: TRAVELING with a DISABILITY - Includes tips for traveling with physical disabilities and advanced trip planning. - a 40 minute discussion + 30 minute Q&A



**1:30pm - Guest Speaker: Lynn Stazzone, A., N.P., M.S. - Brigham Multiple Sclerosis Center**

Nurse Practitioner · BSN · MSN Neurological Rehabilitation · Certificate of Advanced Study in Primary Care · Clinical Interests



→ Topics: What Shared Decision Making actually means emerging Therapies, including brand, biosimilars, biologics and generics - a 45 minute discussion + 35 mins of Q&A

**Program Date: Saturday, November 19<sup>th</sup> 2022**  
**Check-in: 10:45 am ET – Program begins at 11:30am ET**  
**With a Complimentary Lunch**  
**\*\*RSVP Required as showing below\*\***

**Location: Boston Marriott Burlington**  
**One Burlington Mall Road, Burlington MA. 01803**

**Please Register (RSVP) Online: [www.events.msvn.org](http://www.events.msvn.org)**

This program is limited to the MS patient plus a (1) guest.  
If you do not have Internet, please call (888) 871-1664 – Ext 105  
No Walk-ins will be permitted – all must be registered in advance of the event.



Program provided by MS Views and News, a 501C3 not for profit organization  
MS Views and News is **making an impact** on those affected by Multiple Sclerosis  
Program to end at approximately 2:55pm

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## **Don't miss our Chat with Chat webinar series!**

The Next Steps Committee of iConquerMS has launched a webinar series called “Chat with Chat” and you’re invited! Hosted by our research collaborator Chat Ngorsuraches ([iConquerMS’s newest Ambassador](#)) these conversations provide a glimpse at the researchers working with iConquerMS, what they study, and how their work will benefit people with MS.



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 hosted a conversation with Sarah Minden, MD, PhD from Brigham and Women's Hospital about "Use of complementary and alternative medicine (CAM) by members of iConquerMS".

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

### 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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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.



## **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)

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## Help Us Make Strides in MS Research!

### Who Are We?

**MedRhythms** is a digital therapeutics company that uses music to improve walking.

### How Can You Help?

We are developing a device for individuals with multiple sclerosis to improve mobility. **We are seeking volunteers with MS** to walk with the product and provide feedback.

### Interested?

Please email [AppliedResearch@medrhythms.com](mailto:AppliedResearch@medrhythms.com) or call (207) 370-2812 to learn more!





**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.