

August 2022 Newsletter



What is Trigeminal Neuralgia?

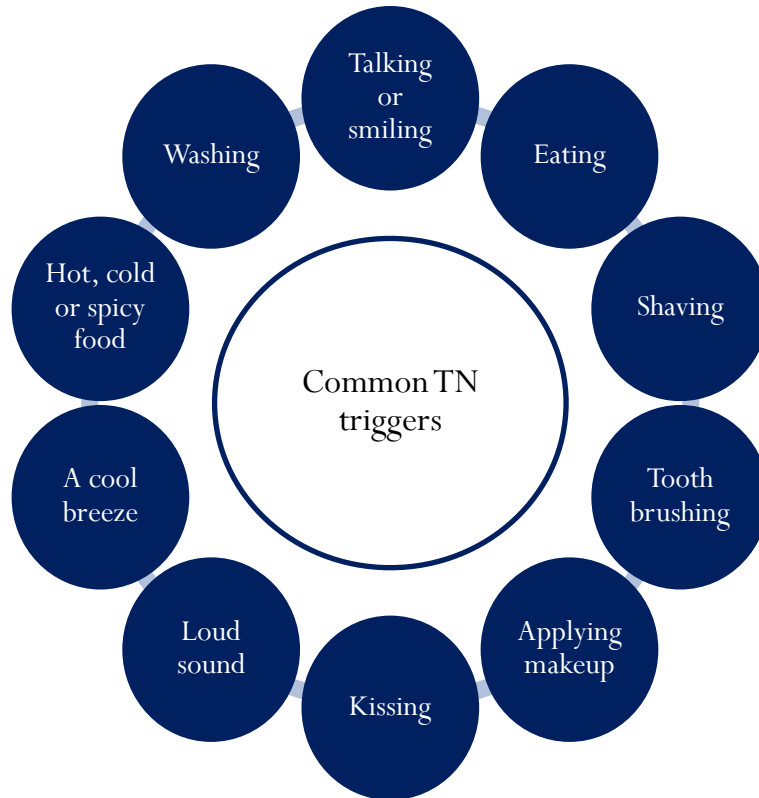
[More than half](#) of people living with MS suffer from chronic pain. Trigeminal neuralgia (TN) is facial pain that is associated with irritation or damage to the trigeminal nerve. TN is one of the most common pain syndromes in individuals with MS and often has a profound impact on quality of life.

The [trigeminal nerve](#) is one of twelve pairs of cranial nerves that provide communication between the brain and the face, head and neck. One trigeminal nerve runs along each side of the face and splits into three branches: the upper stimulates the scalp and the forehead, the middle reaches the nose, cheek and upper jaw, and the lower supplies sensation to the lower jaw and mouth. TN can affect one or more of these branches. The location of the pain depends on which one(s) are affected.



As is often the case with MS, TN manifests itself differently in every individual. It can be excruciatingly painful. Some feel a sudden sharp pain like an electric shock, but for others it may be a more long-lasting aching or burning sensation. These feelings usually occur on one side of the face (unilateral). In rare cases they occur on both sides of the face

(bilateral), but not at the same time. These attacks can happen frequently, lasting anywhere from a few seconds to several minutes. In severe cases they may last an hour or longer. Bouts of pain are often triggered by everyday activities:



Episodes of TN often end with uncontrollable facial twitching, which is why the disorder is also known as tic douloureux. Some people feel warning signs like tingling or achiness prior to the onset of pain, but for most it arrives without warning. Typically, attacks come in waves and then go into remission for months or even years. They often worsen over time, with fewer and shorter pain-free periods. For some individuals, the pain may become continuous.

There is no specific test for TN, a diagnosis is usually based on an individual's description of their pain, including any triggers that may bring it on. A physical or neurological exam may also be done to better understand where the pain is located. Magnetic resonance imaging (MRI) is used to visualize and evaluate the trigeminal nerve.



There are two types of TN. **Primary TN** is typically caused by compression of the trigeminal nerve by a healthy blood vessel at the base of the brain where it meets the spinal cord. The resulting pressure on the nerve causes it to misfire. **Secondary TN** is caused by other factors, such as nerve compression from a tumor or other mass, nerve irritation from sinus surgery or dental problems, injury or trauma to the face, or other health conditions, like MS. In people with MS, TN is most often caused by damage to the myelin sheath around the trigeminal nerve.



According to the [National Institutes of Health](#), TN occurs most often in people over age 50, although it can occur at any age, including infancy. MS is most often the cause of TN in young adults. As is the case with MS, TN is more common in women than in men. The incidence of new cases in the general population is approximately 12 per 100,000 people per year (.012%). [Researchers](#) in Iran

recently determined the estimated prevalence of TN among people with MS is 3.4%, which is substantially higher. A [2017 study](#) suggests that TN may be an early symptom of MS. Results show that TN diagnosis precedes MS diagnosis in 15% of individuals.

A number of medications are used to manage the pain associated with TN. Common analgesics like ibuprofen and aspirin typically don't help. [Carbamazepine](#) (Tegretol) and other [anticonvulsants](#) are often used and are generally most effective in treating primary TN. These drugs act by blocking the trigeminal nerve from firing. Another commonly prescribed medication is [baclofen](#). It relaxes any tight muscles that may be contributing to facial pain. Anticonvulsant medications and baclofen are sometimes used together. While the exact mechanism by which they work is unknown, [tricyclic antidepressants](#) such as [amitriptyline](#) or [nortriptyline](#) also help some individuals with chronic pain. When used for this purpose, these drugs are usually given in doses much lower than those used for depression.



If medication fails to relieve pain or produces intolerable side effects, several surgical options are available. The potential benefits and risks of these approaches should be

discussed with one's healthcare provider. The following [percutaneous procedures](#) are used to treat TN. They target the [Gasserian ganglion](#), which is where the three main branches of the trigeminal nerve join together. These treatments deliberately injure the nerve in order to disrupt any pain signals traveling along it.

Outpatient procedures to treat TN:

Stereotactic radiosurgery

- [High-dose radiation](#) is directed at the Gasserian ganglion causing a lesion on the nerve, which blocks pain signals.

Glycerol rhizotomy

- [Glycerol](#) is injected around the Gasserian ganglion. This numbs the trigeminal nerve and helps to reduce pain.

Balloon compression

- A [tiny balloon](#) is inserted via a thin tube and inflated around the Gasserian ganglion to squeeze it.

Botox injections

- [Botulinum toxin injections](#) around the Gasserian ganglion are being studied as a treatment for TN in MS.

[Microvascular decompression](#) (MVD) is a more major neurosurgical procedure that is used to treat primary TN. It is done under general anesthesia and involves opening the skull to expose the nerve at the base of the brainstem. A tiny Teflon pad is then inserted between the offending blood vessel and the nerve. This pad isolates the nerve from the pulsating effect and pressure of the blood vessel. While it has the potential to provide long-lasting relief, MVD also carries significantly more risk than percutaneous procedures. It's important to note that TN in people with MS is generally caused by demyelination and would therefore not be improved by MVD.



Some individuals with MS turn to [alternative medicine](#) to help manage facial pain. These methods are often used in combination with standard treatments. Dealing with TN can be very draining and lead to lack of sleep, isolation and depression. Some people find that



[yoga](#), [tai chi](#), or [meditation](#) promote a sense of inner peace and wellbeing. A [recent review](#) found that [acupuncture](#) is an effective and safe treatment for primary TN. Investigators state that additional studies should be conducted to verify these findings. In addition, a [2019 study](#) concluded that acupuncture improves the cognitive function and quality of life for

those living with TN. Evidence supporting the effectiveness of other alternative treatments for facial pain is limited. An [analysis](#) done in the 1950's suggested that large doses of vitamin B12 were used to successfully treat TN. A [2007 study](#) concluded that [acupoint injection](#) of vitamin B12 has a better therapeutic effect than that of oral carbamazepine. [Research](#) also shows that [transcutaneous electrical nerve stimulation](#) (TENS) is an effective, easy to use treatment for TN not responding to conventional treatment that has few side effects. A [2017 study](#) suggests that St. John's Wort may be a promising therapeutic option for TN, however these findings were based on a single case study. More research is needed to solidly support the use of St. John's Wort for this purpose.

TN is a painful condition that currently has no cure however there are ways manage it. Many people find relief from TN pain by applying heat to the affected area. It may be useful to keep a symptom diary to see if there is any pattern to TN attacks or any triggers that set them off. Once triggers are identified, steps can be taken to avoid them, if possible. Individuals with TN may have problems eating and with other activities of daily living. There are medical professionals and other resources that can help. For example, an occupational therapist may be able to provide suggestions and equipment to help with daily tasks. A psychologist or other mental health professional may be able to provide encouragement in staying positive. Support groups can help one learn more about new treatments and different ways to cope. It's important for people with MS to speak with their neurologist about any pain they may be experiencing. He or she may be able to help find the right specialist and treatment option to help cope with the pain and effectively manage symptoms.



What are the McDonald Criteria?

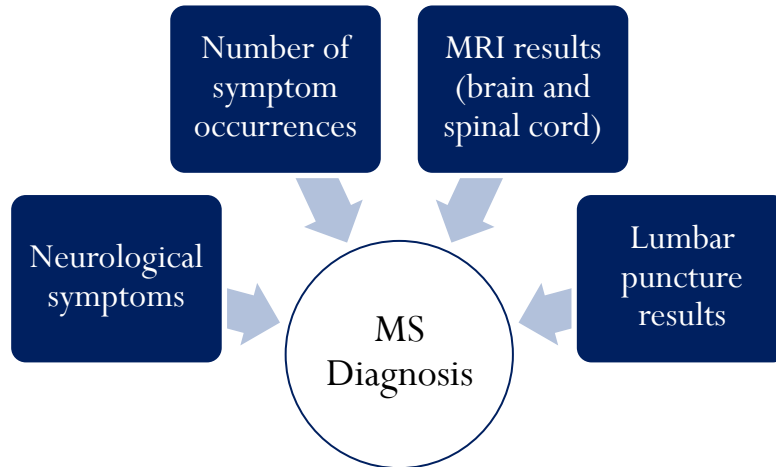
It's important to diagnose MS as early as possible, so that treatment can begin and, ideally, prevent the progression of neurological damage and disability. This can be a difficult task because MS symptoms are different in every person and may be mistaken for other medical issues. There is currently no single test that results in a definitive diagnosis of MS. Neurologists use several tools for



this purpose, including taking a careful medical history, doing a thorough neurologic exam and performing various tests including [magnetic resonance imaging](#) (MRI), [lumbar puncture](#), and blood tests to rule out other conditions. The McDonald criteria are measures aimed at helping doctors diagnose MS more accurately and quickly by guiding them to the most appropriate tests for each individual.

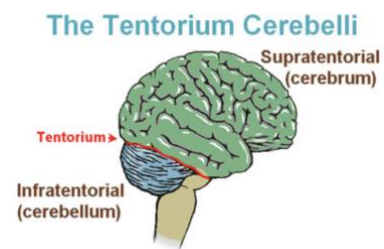
The diagnostic criteria for MS have evolved over time as new health screenings have been developed. The [Schumacher criteria](#) were introduced in 1965 as the first internationally recognized method for diagnosing MS. Diagnosis was based on symptoms identified by the physician. In 1983, the [Poser Criteria](#) became the new standard where the main requirement for diagnosing MS was finding evidence of damage to the central nervous system (the brain and spinal cord) using [lumbar puncture](#) and [evoked potentials](#) (the new laboratory tests of that era). The Poser criteria defined different levels of certainty in the diagnosis of MS, either definite or probable. The [McDonald Criteria](#) (named for neurologist Ian McDonald) were adopted in 2001 and added [magnetic resonance imaging](#) (MRI) to the list of tools a neurologist can use to determine a diagnosis of MS. These guidelines were revised in [2005](#), [2010](#) and, most recently, in [2017](#). It's important to note that the revision of the McDonald Criteria over time does not change any MS diagnosis that is based on an earlier version.

According to the 2017 McDonald Criteria, the following information is used to determine a diagnosis of MS:



An exacerbation or relapse of MS is the occurrence of new neurological symptoms or the worsening of old ones. According to the 2017 McDonald Criteria, neurological symptoms are considered for diagnostic purposes if they last at least 24 hours. They must be due to demyelination of the nerves in the brain or spinal cord and not from another cause, like an infection or other illness. Blood tests are used to rule out other conditions. A history of symptoms may also point to past disease activity.

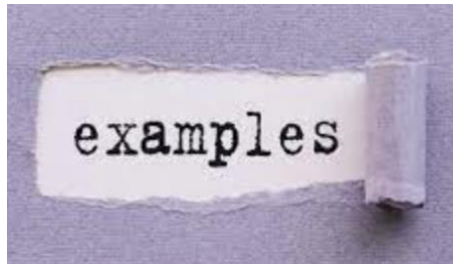
MRI scanning is used to visualize lesions, or damage, in the central nervous system. An individual with MS must have evidence of nerve damage that is “disseminating in space,” or appearing in multiple (at least two) locations. These include three areas of the brain ([periventricular](#), [juxtacortical](#) or [cortical](#), and [infratentorial](#)) and the spinal cord. They must also have evidence of nerve damage that is “disseminating in time,” or happening at different points in time. This can be evidenced by a second relapse occurring at least 30 days from the first one, the appearance of new lesions on MRI, or by new inflammatory lesions alongside older ones that are no longer actively inflamed. A contrast agent called [gadolinium](#) is often used to make this distinction on MRI. Gadolinium enhancing lesions represent areas of active inflammation.



Lumbar puncture is another useful diagnostic test that is used to detect the presence of oligoclonal bands. [Oligoclonal bands](#) are proteins called immunoglobulins that are usually detected in the cerebrospinal fluid (CSF) of people with MS. Their presence is indicative of inflammation in the central nervous system. According to the 2017 McDonald criteria,

testing positive for oligoclonal bands fulfills the criteria for dissemination in time, even if an individual only has evident nerve damage from one time point.

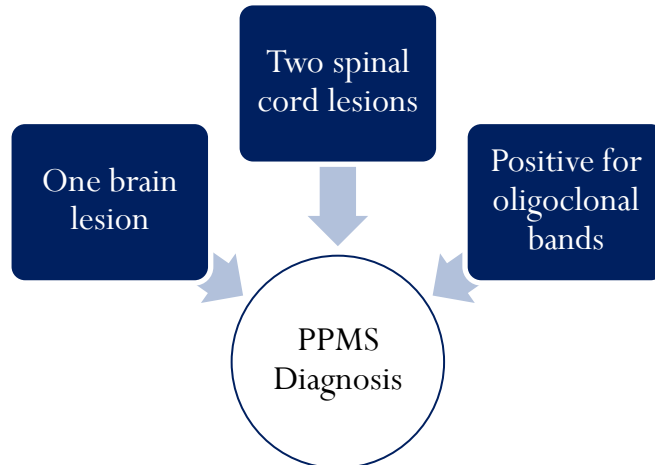
In cases of [relapsing remitting MS](#), a person who has experienced at least two exacerbations and has clear-cut evidence of demyelination in at least two distinct brain areas, can be definitively diagnosed with MS, as they fulfill the requirements for both dissemination in space and time. If an individual has experienced at least two relapses but has evidence of nerve damage in only one brain area, then that individual has fulfilled the criteria for dissemination in time, but not in space. Damage in another brain region must be detected before MS can formally be



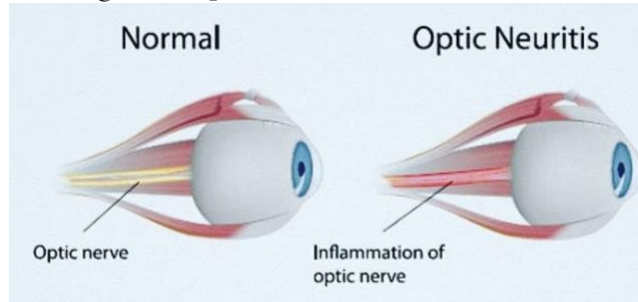
diagnosed. This can be demonstrated by a subsequent relapse implicating a different brain region, or by an MRI scan. For example, if a person with MS has numbness and tingling, then later develops leg weakness, this can implicate different brain regions just by virtue of their symptoms.

Similarly, someone with lesions in two or more brain regions who experienced only one MS exacerbation fulfills the criteria for dissemination in space, but not in time. New damage occurring over time, evidenced by a new lesion on a subsequent MRI scan or by another relapse, is needed for a formal diagnosis. Alternatively, testing positive for oligoclonal bands can be enough to fulfill the criteria for an MS diagnosis in this case.

Diagnosing MS in individuals that have [clinically isolated syndrome](#) (CIS), or [primary progressive MS](#) (PPMS) may present additional challenges. Individuals with CIS have typically had one MS relapse and evidence of damage in one brain region (which does not fulfill the criteria for dissemination in space or in time). A formal diagnosis of MS cannot be made without clear evidence of further damage in other brain regions occurring over time or through the presence of oligoclonal bands. PPMS is characterized by worsening disability from the onset of MS symptoms, without relapses or remissions. A diagnosis of PPMS is determined by worsening disability for at least one year **and** at least two of the following:



[Optic neuritis](#) is common in people with MS, often occurring as the disease’s first symptom. In light of this fact, the optic nerve was proposed as a fifth location to fulfill the criteria for dissemination in space when the McDonald Criteria were last updated. However, the panel performing the [review](#) felt there was insufficient evidence to support its inclusion in the guidelines at that time. In their words, “adding optic nerve involvement detected by MRI or visual evoked potentials as a fifth anatomical site led to a minor improvement in sensitivity of predicting development of a second attack.” The group went on to state that studies to validate testing related to optic neuritis (for example, MRI, [visual evoked potentials](#), or [optical coherence tomography](#)) in support of an MS diagnosis, are a high priority.



Recognizing that everyone’s experience is different, research shows that the process of diagnosing MS has improved over time. A [2019 study](#) concluded that MS can be diagnosed more frequently at the first occurrence of MS symptoms using the 2017 McDonald Criteria than the 2010 version. Investigators state that a careful evaluation is essential in atypical cases to avoid misdiagnoses. According to a [2021 study](#), changes to the diagnostic criteria for MS over the years have resulted in a shorter average

time to diagnosis and less disability progression in people with MS. Investigators compared study participants who received an MS diagnosis based on pre-McDonald criteria in 1994 to those diagnosed based on the 2017 guidelines. The latter saw a 77% reduction in time between CIS and their MS diagnosis, and an 82% reduction in time between CIS and starting MS treatment. Over the entire study period (1994 to 2020), participants whose MS treatment began the earliest were 47% less likely to have an [Expanded Disability Status Scale](#) (EDSS) score of 3.0 or higher than those whose treatment began later.

Research into MS biomarkers and imaging techniques is essential to ensure that MS diagnostic criteria remain current and reflect new health screenings that may become available in the future. These guidelines should be updated and validated in a variety of populations on an ongoing basis to ensure that the fastest and most accurate MS diagnosis is possible for all. Accelerating research efforts like these, that benefit the MS community, is the heart of ACP's mission.



August 2022 iConquerMS Spotlight

And the survey says...



Pediatric Survey

iConquerMS is expanding its community to include children, adolescents and their family members. Three surveys were launched in February 2022 to obtain feedback about participating in research from those who were diagnosed with MS as a child or teen, parents and guardians, healthcare providers and researchers. This information is instrumental as we design and implement support for pediatric MS within iConquerMS. Below is a summary of data that has been collected from 47 participants to date. Interested in completing these surveys? They are still [open](#) and we welcome your input!

1. iConquerMS

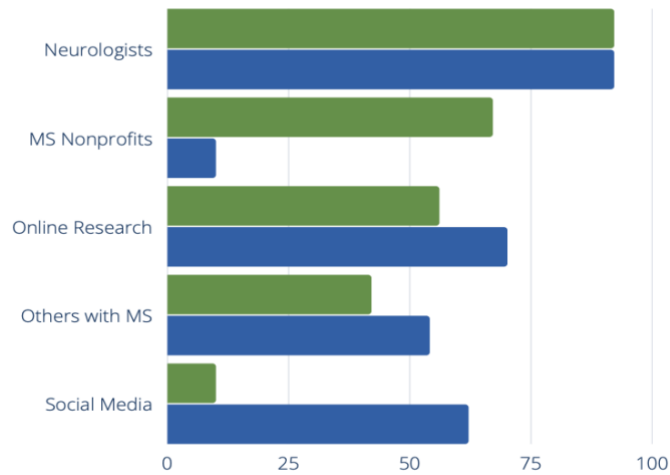
Children & Teens indicated they would likely sign up for iConquerMS. The most common questions included how to join, how much time is required, and what membership entails.

Parents & Guardians indicated they would likely enroll themselves for iConquerMS and sign up their child, if they wanted to participate.



2. Information Sources

The most common sources of information about MS for **Children & Teens** and **Parents & Guardians** were:



3. Most Common Questions About MS

Children & Teens wanted to know:

- Why do I have MS?
- What are MS treatment options, and which work best?
- What to expect with my MS in the future?
- What types of research are taking place?
- How do I manage symptoms?

Parents & Guardians wanted to know:

- How can we manage medication and side effects?
- How can we manage symptoms?
- How can I best support my child?
- How does COVID affect MS?
- How to navigate life transitions (e.g., starting college, the future).



4. Participation in Research

More than half of **Children & Teens** had participated in MS research in the past. The most common ways of learning about these activities were through an MS nonprofit, their neurologist, or a support group.



46% of **Parents & Guardians** had a child that participated in MS research. The most common ways of learning about these activities were through a support group, their child's neurologist, or social media.

5. The Positives of Participating in Research

Children & Teens liked the following about participating in research:

- Being part of finding a cause or cure for MS
- Inclusivity of Black people in research
- Gaining more knowledge about MS
- Financial incentives
- Meeting others with MS and feeling part of a community

Parents & Guardians liked the following about their child participating in research:

- Taking an empowering and active role in their MS and contributing to the MS community
- Ease of participation
- Direct health benefits (e.g., sleep patterns)
- Opportunity to think about and reflect on feelings toward their diagnosis
- Being able to meet peers with MS



6. Motivation

84% of **Children & Teens** were motivated to participate in MS research to help others, contribute to new breakthroughs, and learn more about it.



74% of **Parents & Guardians** said they would like their child to participate in MS-related research. Over 80% were interested in gaining access to new information and in helping other families feel less alone in their situation.

7. Healthcare Providers and Researchers

100% of **Healthcare Providers & Researchers** were interested in working with iConquerMS to conduct pediatric MS research studies. Over 85% were interested in codeveloping studies with our support. They were also interested in providing input on how iConquerMS could serve the research community.

Healthcare Providers & Researchers felt iConquerMS could meet the needs of pediatric patients and families by providing ways to identify gaps in clinical care, create informational resources for younger people about their MS, and provide opportunities for them to participate in research studies that better reflect their needs and priorities.



100% of **Researchers** surveyed had difficulty accessing funding for studies on pediatric MS. Over half had difficulty obtaining access to participants and biosamples. Recruitment strategies included directly inviting patients, asking colleagues to share information, and working with research collaborators. Nearly half of the **Researchers** included the perspective of patients and families when designing research studies.

Healthcare Providers & Researchers felt the most needed resources for those with pediatric-onset MS are:

- Mental health resources and support groups
- Videos, webinars and forums for kids to express their concerns
- Better explanations of MS and the available therapies
- Information about cognitive testing and school accommodations
- Tools and better access to care for those with limited socioeconomic means

August 2022 Research Spotlight

RESEARCH OPPORTUNITIES

Research opportunity information may be provided on behalf of an external organization. Please refer to the contact information within each listing to identify the contact for questions or comments.



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 or call (207) 370-2812 to learn more!



The University of North Texas Department of Kinesiology, Health Promotion, and Recreation is conducting a Research Study on Physical Activity Among Hispanic Persons with Multiple Sclerosis

The research will take place online.

You may be eligible if:

- You are over the age of 18
- You have been diagnosed with multiple sclerosis
- You identify as Hispanic/Latino
- You speak English or Spanish as a primary language

You may qualify to participate in a research study examining physical activity thoughts and behavior in Hispanic adults with multiple sclerosis.

Participation in the study includes one online survey that will be completed in 20-30 minutes. Participation is voluntary. You will receive compensation after completing the survey if you provide an e-mail address.

Please use the link below to complete the survey and contact the Principal Investigator with any questions using the study title “Theoretical Correlates of Exercise Behavior Among Hispanics with MS” Stephanie L. Silveira Stephanie.silveira@unt.edu

Survey Link: https://unt.az1.qualtrics.com/jfe/form/SV_1SogD4QwBBuvEc6



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



A study looking at language usage among people with disabilities – all adults with disabilities are welcome to participate!

What is the study about?

This research attempts to gather evidence on the preference between identity-first and person-first language by and for people with disabilities. The lead researcher is a graduate student in the University of Washington's department of Computer Science and Engineering as a member of multiple labs focused on accessibility in computing.

Why participate?

The topic of language preference has been discussed often, but often while excluding community and individual perspectives. The research data gathered will help to work towards more consistent respectful language usage in future projects. Participants will contribute to a public website that features a visualization that explores the ways different backgrounds (age, country, gender) may or may not affect language preference.

Who can participate?

All people with disabilities over the age of 18 who have access to and can use a computer and access to the internet are welcome to participate.

How to participate:

Follow this link: <https://bit.ly/disability-language-survey> to access our participant survey. It should take around 5 minutes to complete.



**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.