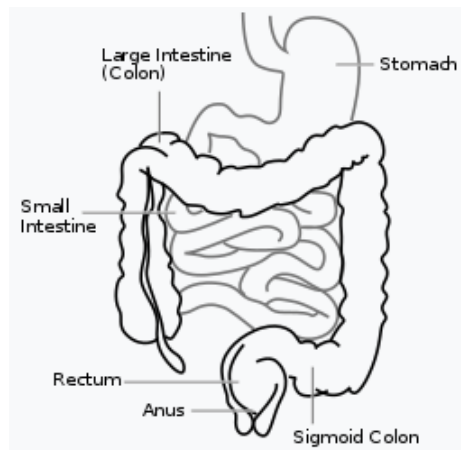


July 2021 Newsletter



MS, You and Number Two

Bowel control is a complex process that involves the coordination of many different nerves and muscles. The bowel, also known as the colon or large intestine, makes up the lower portion of the digestive system. Its primary function is to prepare food that can't be used in the body for disposal. Food is moved through the digestive system by a propulsive action called [peristalsis](#). Digestion begins in the stomach, where this motion mixes food with gastric juices, turning it into a thin liquid. Digestion continues in the small (or upper) intestine and water is reabsorbed from the food as it moves to the large intestine. By the time stool reaches the bowel it has lost much of its water content. The rectum is the last four to six inches of the digestive system. It remains empty until just before a bowel movement. As the rectum fills, messages are sent to the brain that a bowel movement is needed. From the rectum, the stool passes into the anal canal, which is guarded by two sphincter muscles. The stool is allowed to pass into the anal canal by an internal sphincter, which opens automatically when the rectal wall is stretched by a mass of stool. An external sphincter controls



whether or not the stool is voided. This muscle is opened voluntarily, so that bowel movements can be performed at appropriate times.

If the contents of the bowel move too fast, not enough water is removed and the stool reaches the rectum in a soft or liquid state known as diarrhea. If movement of the stool is slow, too much water may be absorbed by the body, making the stool hard and difficult to pass. This condition is constipation. Constipation can prevent any of the stool from being eliminated, or it can result in a partial bowel movement, with part of the waste retained in the bowel or rectum. Constipation is the most common bowel complaint in MS. Diarrhea and incontinence (loss of control) are less common. A [recent study](#) showed that almost half of people with MS experience constipation and almost one third have fecal incontinence. Results show that these symptoms are associated with higher levels of fatigue and disability.



MS can disrupt bowel function in a number of ways. For example, nerve damage can slow the signals to the anal sphincters, block the natural increase in peristalsis following meals and prevent pelvic floor muscles from relaxing (which is necessary for stool to exit the body). Weakened or spastic abdominal muscles can also make the actual process of having a bowel movement more difficult. Common MS symptoms like depression or a decrease in physical activity can lead to slow movement of fecal material through the colon. It's important to note that not all bowel dysfunction is caused by MS, it can be due to other health conditions. Diarrhea may stem from food sensitivities/allergies or consuming contaminated food/water. It can also be due to a viral, bacterial or parasitic infection. A number of medications (some of which are used to treat MS symptoms) have the potential to cause constipation, such as [antidepressants](#), [diuretics](#), [opiates](#), and [antipsychotic](#) drugs. Ironically, one of the most common causes of constipation is voluntarily delaying a bowel movement. This may be done to save time on a busy day, or when a trip to the bathroom isn't possible. Eventually the rectum adapts to the increased bulk of stool, the urge to eliminate subsides and more water is resorbed making the stool harder and more difficult to pass.

It may be helpful to set a regular time to go to the bathroom and to plan plenty of time for this routine. In general, the best time of day to empty the bowel is about a half hour after eating. This is especially true after breakfast. Keeping a diary of bowel patterns can also be useful. This can give some insight into the effects of illness, medication and other lifestyle factors on bowel function. The [Bristol Stool Chart](#) is a free mobile app for this purpose that allows sharing of data with a health care professional. Sometimes it's possible to stimulate a bowel movement by gently massaging the abdomen in a clockwise manner. Decreasing the angle between the rectum and the anus can also make it easier to go. This can be done by leaning forward while sitting on the toilet and placing the elbows on the knees. Placing the feet on a footstool so the knees are higher than the hips can create the same desired body angle.

Drinking plenty of fluids is essential to maintain regularity. As we discussed [last month](#), bladder dysfunction is common in people with MS. Some attempt to relieve bladder symptoms by reducing their fluid intake and this makes constipation worse. Therefore, it's important for people with MS to address any bladder issues they may be experiencing so that adequate fluid intake (which is critical to



bowel functions) will be possible. A hot beverage may help to stimulate a bowel movement as this increases peristaltic activity in the digestive system. Some people find drinking prune juice helps to move things along. Adding fiber to the diet is also key because it holds water and is resistant to digestion. This helps keep the stool moving by adding bulk and by softening the stool. Good sources of fiber include fresh fruits and vegetables, or whole grain breads and cereals. Emotions can also affect bowel function. For this and many other reasons, keeping unnecessary stress to a minimum is a good idea. As discussed in our [April 2019 newsletter](#), relaxation techniques like mindfulness can be helpful in this regard.



A laxative is a type of medication that helps a person empty their bowels. They are generally used to relieve constipation. Many different types of laxative are available over the counter, each works in a different way and can be used for varying periods of time.

Types of Laxatives

[Emollient laxatives](#), or stool softeners, help to wet and soften the stool so it is easier to pass. They are gentle enough for regular use and usually work in 12 to 72 hours. Stool softeners are generally recommended for people with temporary or mild, chronic constipation.

[Bulk-forming laxatives](#), or fiber supplements, form a gel in the stool that helps it hold more water. It becomes softer and bigger as a result, which stimulates movement in the intestine to help pass the stool more easily and quickly. Taken daily with one or two glasses of water, they are generally safe to take for long periods and are a good option for people with chronic constipation. However, they take longer than other laxatives to work, having their full effect in 48 to 72 hours.

[Hyperosmotic laxatives](#) draw more water into the intestines which helps soften the stool to help it move more easily. Hyperosmotic laxatives can also be used for longer periods with little risk of side effects, but they should not be used continuously for longer than one week without consulting a doctor. Like bulk-forming laxatives, they're a good option for people with chronic constipation and they take about the same amount of time to work (48 to 72 hours).

[Lubricant laxatives](#), or mineral oil, coat the stool and intestines to prevent water loss. They also lubricate the stool to help it move more easily. Mineral oil typically works in 6 to 8 hours, but should not be used on a regular basis because it can interfere with the body's absorption of [fat-soluble vitamins](#). Lubricant laxatives are typically only good options for immediate relief of short-term constipation.

[Stimulant laxatives](#), as the name implies, stimulate and increase the movement of the intestines. Taken orally, this type of laxative will usually work in 6 to 12 hours. Stimulant laxatives should not be used on a regular basis because they can cause dehydration and [electrolyte imbalances](#).

Suppositories are an option if oral laxatives fail. They provide the fastest relief of constipation, usually within 15 to 30 minutes. A suppository is a medication that is inserted into the rectum, where it then dissolves and enters the bloodstream. A [glycerin suppository](#) is a form of



hyperosmotic laxative that is typically administered half an hour before attempting a bowel movement. This can be repeated over the long term in order to establish a regular bowel routine (even on a permanent basis). A [Dulcolax suppository](#) is a form of stimulant laxative that must be carefully placed against the rectal wall for maximum effectiveness (it doesn't work as well if inserted into the stool). It's important to note that Dulcolax suppositories cannot be used for long periods because they are much more habit-forming than glycerin suppositories.

An [enema](#) can be used to clear hardened stool that is impossible to pass due to severe constipation. This involves instilling a saline solution directly into the rectum with a bulb syringe, which helps push waste out, typically within an hour. Enema kits are available over the counter for home use, but it's important to consult with a physician before using one. [Rectal irrigation](#) (sometimes called anal irrigation) is a similar treatment that is used for longer term bowel management. This involves introducing warm saline into the rectum and lower colon using a rectal catheter. The saline stimulates the bowel muscles and flushes out the stool, leaving the lower half of the bowel empty. Rectal irrigation can be performed at home and, when done on a regular basis, is very effective at achieving full continence and preventing constipation.



When dealing with diarrhea, it may be helpful to eat bland foods like bananas, rice, applesauce, or toast (otherwise known as the BRAT diet). It's important to stay hydrated as the body can lose a lot of fluid and electrolytes this way. Caffeinated, alcoholic and sugary drinks can worsen dehydration. Clear broth and water are helpful, and sports drinks are a good choice because they replace the electrolytes that are lost. A number of [medications](#) are used to treat diarrhea, both over the counter and prescription. These drugs work by slowing peristalsis, making stools firmer and pass less frequently. It's important to note that antidiarrheal medications should not be taken if there is any sign of an infection, such as fever or blood in the stool. [Pelvic floor exercises](#) can help reduce the chances of bowel accidents. The pelvic floor muscles help to support the bladder and

bowel, plus the womb in women. When these muscles become slack it can weaken the sphincter muscles in the anal canal allowing the involuntary passing of stool. As discussed last month, [sacral nerve stimulation](#) has been shown to be an effective treatment for fecal incontinence with favorable long-term results. [Research](#) also shows that injection of [collagen](#) into the anal sphincter is a safe and effective way to help thicken the tissues, thus preventing soiling and improving control. Results show that repeat injections are often necessary.

There are a number of [products](#) available to protect against soiling from fecal incontinence, including protective underwear/briefs and disposable liners. Using this type of protection can afford confidence, especially in situations where getting to the restroom could be difficult. For those that may feel anxious about leaving the house, a number of [mobile phone apps](#) are available to find the nearest bathroom. It may also be helpful to wear easily removable clothes, for example pants with elastic waistbands and bring a change of clothes, just in case. For around the house, [bed pads and mattress protectors](#) can help keep the bed clean and dry. There are also [covers and pads](#) available for chairs.



Bowel dysfunction can not only cause a great deal of discomfort and embarrassment, it can also aggravate other MS symptoms. It's important for people with MS to stay active, eat a healthy, balanced diet with plenty of fiber and drink enough fluids to regulate the bowel and keep stools at the right consistency. When good bowel habits don't suffice, there are a number of effective treatment options available for managing most symptoms of bowel dysfunction. It's important for people with MS to discuss any bowel issues they may be experiencing with their healthcare providers. Early medical evaluation is important to determine their cause and choose the best treatment strategy so they no longer impact, or have as much impact, on daily life.



MS and COVID-19 Vaccines

Three COVID-19 vaccines have emergency use authorization from the Food & Drug Administration in the United States.

Two [mRNA vaccines](#), made by [Pfizer-BioNTech](#) and [Moderna](#), require two doses for maximum protection. A third [viral vector vaccine](#), made by [Johnson & Johnson](#) (J&J) requires a single dose. According to the National MS Society, “Whether you receive the Pfizer BioNTech, Moderna or J&J vaccine, it takes two weeks after being fully vaccinated before you are considered protected.”



The National MS Society’s [COVID-19 vaccine guidance](#) for people with MS was updated in June 2021 to say, “The science has shown us that the COVID-19 vaccines are safe and effective. Like other medical decisions, the decision to get a vaccine is best made in partnership with your healthcare provider. Most people with relapsing and progressive forms of MS should be vaccinated. The risks of COVID-19 outweigh any potential risks from the vaccine. In addition, members of the same household and close contacts should also be vaccinated against COVID-19 when available to decrease the impact of the virus.” According to the guidance, the COVID vaccines are safe to use with MS medications. These recommendations are based on clinical trials of the general population and studies of other vaccines administered to people with MS. It’s unclear how many subjects with MS or those on disease modifying therapy (DMT) were included in the COVID-19 vaccine clinical trials. This may leave people with MS wondering whether or not it’s safe to get vaccinated and if it will be effective in light of their MS treatment. These are hot topics in MS research and numerous studies are underway to provide clarity.



A [recent study](#) concluded that the Pfizer vaccine is safe and effective in people with MS. As part of this research, over 500 adults with MS received the Pfizer vaccine between December 2020 and January 2021 (555 MS subjects received the first dose and 435 received the second dose in that timeframe). The most common adverse events from the vaccine were the same as reported in the general population (pain at the injection site, fatigue, and headache). These symptoms were more common after the second dose than after the first dose. Results show the vaccine does not increase the risk of MS relapse activity and it is highly effective over the short term. Investigators state that longer follow-up is necessary to better evaluate its protection over time.

As discussed in our [January 2021 newsletter](#), vaccines help develop immunity by imitating an infection. The immune system recognizes the “vaccine germs” as foreign invaders just as it would the “disease germs” and responds by making proteins called antibodies. Antibodies help resolve an infection by destroying the germs. They also provide protection from future infections by remaining in the bloodstream. If the same germs attack again, they are destroyed before they cause illness. Some MS DMTs act by suppressing this immune response and this could reduce the effectiveness of the COVID-19 vaccines in people taking these medications. Two recent studies explored this important subject, with very interesting findings. [Researchers](#) in the Netherlands looked at SARS-CoV-2 antibody levels (the virus that causes COVID-19) in 546 subjects with MS, 405 of which were on a DMT. They found antibodies were less prevalent in subjects taking beta interferon drugs (Avonex, Rebif, Betaseron, Extavia and Plegridy), glatiramer acetate (Copaxone) and ocrelizumab (Ocrevus). These data imply that B-cell depletion could influence SARS-CoV-2 antibody production in people with MS. [Investigators](#) in Israel evaluated the immune response in 125 MS subjects and healthy control subjects one month after the second dose of the Pfizer vaccine. MS subjects were either untreated or under treatment with fingolimod (Gilenya), cladribine (Mavenclad), or ocrelizumab (Ocrevus). Results show that healthy subjects and MS subjects that were untreated or treated with cladribine had high antibody titers for SARS-CoV-2. Only 22 percent of MS subjects treated with ocrelizumab developed a protective immune response. Most fingolimod-treated MS subjects failed to develop SARS-CoV-2 antibodies.



A number of clinical trials are underway to better understand the immune response in people with MS after COVID infection and COVID vaccination in the context of MS treatments.

Current COVID-19 clinical trials in people with MS

[Researchers](#) in Switzerland are studying the immune response after COVID-19 infection in subjects with MS treated with various DMTs and subjects with MS not on treatment.

A [clinical study](#) is underway in Oregon to determine whether DMTs affect the ability to mount and sustain an immune response following COVID vaccination in people with MS.

[Investigators](#) at Saint Barnabas Medical Center in New Jersey are evaluating the effect of MS DMTs on antibody responses to the Moderna vaccine in subjects with MS.

The [VIOLA study](#) (Vaccine-generated Immunity in Ocrelizumab-treated Patients) will shed light on the immune response in MS subjects on ocrelizumab (Ocrevus) receiving the Pfizer and Moderna vaccines.

[Researchers](#) in Massachusetts are evaluating whether or not subjects with MS currently receiving treatment with ocrelizumab (Ocrevus) or natalizumab (Tysabri) produce antibodies following COVID-19 vaccination.

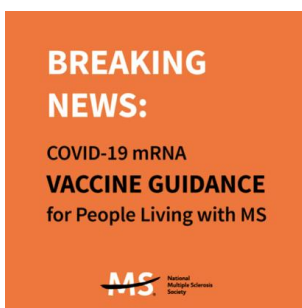
Investigators from Novartis in Germany are conducting the [KYRIOS study](#) to evaluate the immune response following COVID vaccination in subjects with relapsing remitting MS taking ofatumumab (Kesimpta) and the [AMA-VACC study](#) to better understand the immune response following COVID vaccination in subjects with secondary progressive MS taking siponimod (Mayzent).

[Investigators](#) in France are conducting a multicenter study of immunocompromised people, including people with MS, to better understand their immune response after receiving the Pfizer vaccine with respect to the UK and South African variants and any other COVID variants that may emerge.



In collaboration with researchers at Case Western Reserve University and Massachusetts General Hospital, and with funding support from the National MS Society, the research team at iConquerMS is conducting the [COVER-MS study](#) ([COVID-19 Vaccine Response in MS](#)) to collect information from iConquerMS members related to their experiences with COVID-19 vaccines. Participants are asked to

complete surveys on the [iConquerMS portal](#) at different timepoints. These surveys contain questions about demographics, MS characteristics, COVID-19 infection, any COVID-19 vaccines received, reactions to them, and any MS symptoms experienced before and after vaccination. According to the July 6 [status report](#), over 1,250 network members have enrolled in COVER-MS, 84% of whom are female. The vast majority of participants are white (92%), 68% have relapsing remitting MS, 29% have progressive MS and the remaining 2% have clinically isolated syndrome. With regard to COVID vaccines, 57% of subjects received the Pfizer vaccine, 35% received the Moderna vaccine and 5% received the Johnson & Johnson vaccine. 955 participants received their first COVID-19 vaccine with 61% experiencing side effects. 640 subjects received their second dose with 71% reporting side effects. The majority of side effects were reported to be mild or moderate, with injection site pain, fatigue and headache being the most common. Regarding DMT use, 23% of respondents had not taken any DMT in the year prior to participation in the study, 28% had been on B-cell depleting therapies and 49% had taken other DMTs in the same time period. The initial data analyses are underway, focusing on factors that affect who experiences side effects and how severe they are. Stay tuned for these real-world results, which will provide a better understanding of the effects of these vaccines in the MS population! If you are an iConquerMS member who has received a COVID-19 vaccine and you haven't participated in COVER-MS, please login today and share your experience by clicking on "Participate in the COVID-19 Vaccination Study." Not yet a member? Please [join](#) iConquerMS and power research with your data!



The Society recently issued [guidance](#) on dosing modifications for DMTs in people with stable MS receiving a COVID-19 vaccine. As stated in the guidance, "Based on expert consensus and available data, we offer the following guidance regarding COVID-19 vaccination for people on MS disease modifying therapies (DMTs). This guidance applies to people with MS ages 12 and older and only for the vaccines authorized for use for their age in the United States. This guidance will be updated as new data are

available... **The Pfizer BioNTech, Moderna and Janssen/J&J vaccines are safe for people with MS, and they are safe to use with MS DMTs.** The vaccines are not likely to trigger an MS relapse or have any impact on long-term disease progression. The risks of COVID infection far outweigh any potential vaccine risk, and persons with MS are encouraged to get the vaccine as soon as possible. Most DMTs are not expected to affect the responses to these vaccines, though some may make the vaccines less effective. Coordinating the timing of vaccine administration with these DMTs may provide the best vaccine response.” Please see the [full guidance](#) for details.

According to recent [guidelines](#) issued by the Centers for Disease Control and Prevention (CDC), most healthy people who are fully vaccinated can get back to normal activities without wearing a mask or social distancing. Because researchers are still learning how the vaccines work in people with weakened immune systems, the CDC warns that people with certain health conditions, like MS, or who are taking immune-suppressing medications may not be fully protected against COVID-19 even if they’re fully vaccinated. As a result, these individuals may need to continue wearing a mask for the foreseeable future. The Society [echoes](#) this recommendation, stating, “For people with MS, especially those in high-risk groups and those taking a DMT that might reduce the effectiveness of the vaccines, the safest approach is to continue wearing masks, practicing social distancing, and performing regular hand-washing.”



It’s important for people with MS to consult with their healthcare providers on COVID-19 vaccine questions, and to coordinate vaccination with their MS treatment. Researchers around the world, including ACP through the COVER-MS study, are gathering data specific to the safety and effectiveness of these vaccines in the MS population that will provide clarity in these decisions. The core of ACP’s mission is to facilitate research efforts like these, that significantly impact the MS community.



July 2021 iConquerMS Spotlight

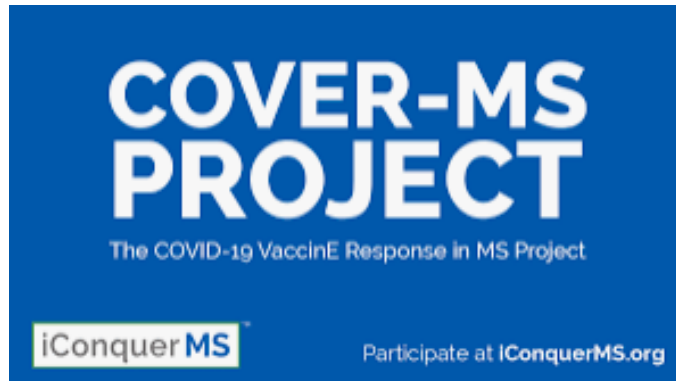
Share your experiences with COVID-19 vaccines

The current guidance on COVID-19 vaccination for people with MS from the National MS Society is based on data from the general population in the vaccine clinical trials and data from studies of other vaccines administered to people with MS. We do not know how many people in the vaccine clinical trials had MS. Data on the experiences of people with MS who have received these vaccines is still becoming available. The [COVER-MS study](#) (COVID-19 VaccinE Response in MS) is underway to collect this valuable information. This study is a collaboration between the iConquerMS team, and researchers at Case Western Reserve University and Massachusetts General Hospital, and is funded by the National MS Society.



All adults affected by MS are eligible (21 or older) and welcome to participate. Subjects will be asked to complete a few short surveys on the iConquerMS portal at different timepoints. These surveys contain questions about demographics, MS characteristics, COVID-19 infection, COVID-19 vaccines received, reactions to them, and any MS symptoms experienced before and after vaccination. The data collected will provide a better understanding of the short- and longer-term effects of the vaccines in the MS population.

Real-world data from COVER-MS will complement the available guidance and provide additional assurance for those with MS who are planning to get vaccinated. If you are an iConquerMS member that has received a COVID-19 vaccine, please [login](#) today and share your experience by clicking on “Participate in the COVID-19 Vaccination Study.” Not yet a member? Please [join](#) iConquerMS now and power research with your data!



July 2021 Research Spotlight

RESEARCH OPPORTUNITIES



University of Washington Community Health Study

The University of Washington’s (UW) Department of Rehabilitation Medicine is conducting a study to increase our knowledge about aging with a disability.

Participation in this study would include either 8 telemedicine visits with a wellness coach over 6 months or continuing with your normal care, as well as filling out 4 surveys over 12 months. You are eligible for financial compensation for surveys you fill out along the way.

Researchers at UW are seeking participants who:

- Are ages 45 – 64
- Have been diagnosed with a neurologic or muscular medical condition that creates difficulties or challenges in your daily living
- Experienced symptoms of this condition prior to age 40

Are you ready to learn more or get started? Contact the Research on Aging, Disability and Resilience (RADAR) Lab by calling 1-866-928-2114 or emailing communityhealthstudy@uw.edu.



UW Medicine
DEPARTMENT OF
REHABILITATION MEDICINE

Diagnosed with Multiple Sclerosis within the past 3 years?

What is it?

The Coping & Adjusting to Living with Multiple Sclerosis (CALMS) study is looking for adult participants diagnosed with MS within the past 3 years.

What is involved?

This study involves 1x week telephone or video Cognitive Behavioral Therapy (CBT) sessions with a counselor for 7 weeks, completing questionnaires and game sessions (receive up to \$175 for completing questionnaires and games).

Eligibility:

- 18 years of age, or older
- Diagnosed with Multiple Sclerosis within the past 3 years
- Experiencing feelings of unease/stress regarding the recent MS diagnosis
- Read, write, and understand English

Interested in participating?

Contact the study team at 1-866-928-2114 or CALMS@uw.edu.



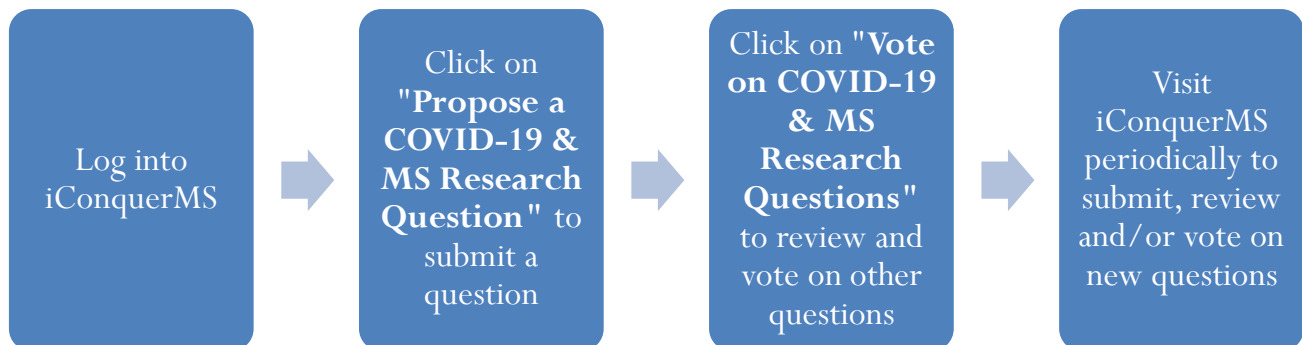
Learn more or get started at iConquerMS.org

Power MS Research With Your Questions and Priorities!

iConquerMS is leading the movement to include the patient perspective in every step of MS research. Now, network members can play a larger role than ever before in initiating and collaborating with researchers on studies that will expand knowledge in areas that matter most to people affected by MS.

iConquerMS members have always been able to submit research questions to the initiative. It's now possible to comment and vote on questions submitted by the community through the newly launched [Our Questions Have Power](#) program. Questions that are high priority for the iConquerMS community will be shared with researchers and funders, who will work in collaboration with the iConquerMS community to develop them into research studies.

Participation is easy!



If you are not already a member, please consider [joining](#) iConquerMS, the only people-powered research network for MS. Add your voice to those working together to improve MS care and bring us closer to a cure!