

# March 2021 Newsletter



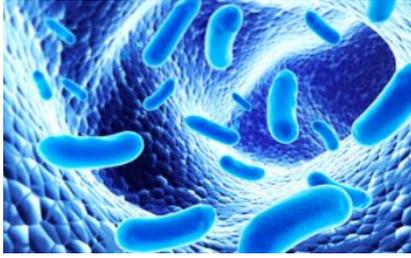
## What's New in MS Research?

MS is a chronic, unpredictable and often disabling disease of the central nervous system that affects nearly one million people in the United States. In recent years, new medications have become available to help slow the progression of the disease and manage its symptoms. Researchers continue to piece together new information as they work toward ultimately finding a cure. Read on about some interesting findings that have been published in the last 6 months.



The [causes of MS](#) are still unclear, however researchers are making inroads into this important topic. For example, a [Danish study](#) recently concluded that children of diabetic mothers may be at an elevated risk of developing MS. Data showed that MS risk among individuals whose mothers were diagnosed with diabetes before pregnancy was 2.3 times higher than those with nondiabetic mothers. Of note, investigators concluded that MS risk was not significantly affected by having a mother diagnosed with diabetes during pregnancy or having a diabetic father.

Two papers were recently published looking at the role of the [microbiome](#) in the development and progression of MS. A team of researchers from Germany, Spain and



Switzerland [reported](#) that a protein called “IL-17” (which is generated in the gut to regulate its microbiome) appears to be a critical driver in the likelihood of autoimmune disorders like MS in mice. Another [study](#), also in mice, recently found that a subset of brain cells (astrocytes) can turn off inflammation within the brain, based on signals regulated by the bacteria in the gut. Figuring out how to harness this beneficial activity in humans may lead to new treatment approaches for MS, including probiotics to alter the balance of gut bacteria.

Significant progress has been made in the treatment of MS with a [wide variety](#) of oral and injectable disease modifying therapies (DMTs) available for relapsing and progressive forms of the disease. Two studies, published in early February, draw conclusions about the effectiveness of these treatments. The [first study](#) suggests that DMTs are effective at improving disability outcomes in relapsing-remitting MS (RRMS) over the long term. The [second study](#) identified two factors associated with treatment failure in RRMS. Data showed that DMTs were less effective in subjects who started treatment when they were younger than 26 years old, or if they had two or more relapses in the previous year. Interestingly, results suggest that the presence of enhancing lesions on MRI (which indicate disease activity) did not significantly affect treatment outcome.



The following research sheds new light on a number of FDA-approved MS treatments. A [small study](#) recently found that intravenous cladribine (Mavenclad) may be as safe and effective as oral cladribine at reducing relapses, improving MRI activity, and slowing disease progression in individuals with active MS, with a reasonable safety profile. [Further analysis](#) of data from the [EXPAND study](#) recently showed Siponimod (Mayzent) had a significant benefit on cognitive function in patients with secondary progressive MS (SPMS). A recent [review](#) concluded that treatment with dimethyl fumarate (Tecfidera) was associated with a higher risk of adverse events, such as flushing, gastrointestinal issues and lymphopenia, over the short term. More research is required to determine its long-term safety. Ocrelizumab (Ocrevus), which can be used to treat RRMS, is also the first approved medication for primary progressive MS. A recent [study](#) determined that people with MS treated with

ocrelizumab experience lower work and activity impairment than those treated with other DMTs.

Three publications reveal new findings about MS and its treatments in the context of [COVID-19](#). German researchers published a [review](#) of 873 published cases of people with MS and COVID-19 infection as of December 2020. Results suggest immunosuppressive therapy itself does not appear to be a substantial risk factor for the virus. With regard to the different DMTs, the most COVID-19 cases were reported in those receiving [anti-CD20 treatment](#) (317 cases). There was a 4 percent mortality rate from COVID-19 infection among people with MS and 3 percent required ventilation therapy. Severe and fatal cases of COVID-19 occurred in subjects not taking DMTs, those with previous cardiovascular diseases, or with higher levels of disability. Researchers suggest that DMTs could be protective, either directly or indirectly, by reducing MS disease activity. A [second study](#)



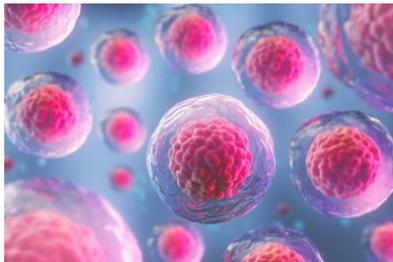
found that, overall, people with MS have similar incidence, risk factors and outcomes for COVID-19 as the general population. Data also showed that subjects treated with an anti-CD20 therapy for a longer period of time appeared to be at a higher risk of COVID-19 and less than 20 percent developed antibodies to the virus. Only increased age was related to the severity of COVID-19 infection. [Researchers](#) in Croatia identified 33 people with MS who had to delay treatment with ocrelizumab by approximately one month due to COVID-19. None of the subjects had a relapse during this period and there were no other clinical consequences from the delay.

Several novel MS treatments are working their way through the research pipeline, with mixed results. A [clinical trial](#) done at 90 MS clinics across 13 countries recently showed that high dose biotin did not significantly improve disability



or walking speed in subjects with progressive MS. Results also suggest this treatment had a negative safety profile. Researchers at Oregon Health & Science University developed a compound, called [sobetirome](#), that mimics the myelin-generating effect of thyroid hormone by stimulating the maturation of its precursor cells (known as oligodendrocytes). [New results](#) show promise for sobetirome's ability to stimulate the repair of myelin in mice. [German researchers](#) recently published results from a study looking at the effectiveness of an [mRNA vaccine](#) to treat MS in mice. Mice with an MS-like disease were given an mRNA

vaccine containing the code for part of a myelin component. Data revealed that the mice experienced less severe disease than would have been expected and their normal protective immune responses were not compromised. It's important to note that early findings in animal models require considerable study before they can be applied to humans.



Recent advances have also been made in [stem cell](#) research. Italian [investigators](#) published a paper in January looking at outcomes of 210 people with MS who received autologous hematopoietic stem cell transplantation (HSCT) from 1997 to 2019. Nearly all of them had either RRMS or active SPMS. After ten years, 65 percent of the subjects continued to

experience no worsening of disability. This rose to 71 percent among those with RRMS. [Researchers](#) from Lithuania conducted a smaller study of 24 subjects with active RRMS that failed conventional MS treatments and underwent HSCT. Results showed information processing speed and verbal learning were significantly improved one year after stem cell therapy. Researchers in Israel and Germany recently published results from a [study](#) looking at the optimal route of administration, and the safety and effectiveness of mesenchymal stem cell (MSC) transplantation in 48 subjects with active progressive MS. Results showed treatment with MSCs was well-tolerated and had short-term benefit. Intrathecal administration was more effective than intravenous administration. A larger clinical trial is needed to confirm these findings.

We've covered the general topic of [alternative therapies](#) for MS, [cannabis](#) and the practice of [mindfulness](#) in previous newsletters. Recent studies have shown a number of these unconventional treatments to be beneficial. Danish researchers recently published [results](#) from a study that showed treatment with medical cannabis oils was safe and well tolerated, and resulted in a reduction in pain intensity, spasticity and sleep disturbances in subjects with MS. [Investigators](#) in Iran found that 8 weeks of group-based cognitive hypnotherapy significantly improved the psychological well-being of subjects with MS. Another [study team](#) in Iran looked at the effects of 3 months of cognitive rehabilitation versus donepezil therapy on memory, attention, depression, and quality of life in subjects with MS. Subjects on both treatments showed improvement in all areas, however cognitive rehabilitation was superior altogether. A [clinical trial](#) conducted at the Ohio Health



Multiple Sclerosis Center showed that 4 weeks of mindfulness meditation training improved processing speed above and beyond adaptive cognitive training, or no intervention at all.

While there is no specific [diet](#) that will prevent or cure MS, scientists continue to find evidence that eating certain foods and nutrients, and avoiding others, may help a person's MS symptoms and disease activity. In November, Yale researchers published a [study](#) suggesting the abnormal immune system response that causes MS may be triggered by the lack of a



specific fatty acid in fat tissue, called oleic acid. Oleic acid is found in cooking oils, meats, cheese, nuts, sunflower seeds, eggs, pasta, milk, olives, avocados, and other foods. However, it's important to note that further study is needed to determine whether consuming more oleic acid would reduce disease activity in people

with MS. Italian researchers conducted a [study](#) looking at the life and dietary habits of 435 people with MS. Their findings suggest the Mediterranean diet may have a beneficial effect on MS course and disability, and this effect is likely mediated by a change in the gut microbiome.

It's a well-known fact that [exercise and physical fitness](#) are beneficial, regardless of an MS diagnosis. Researchers in Canada recently published a [review](#) of evidence from animal models of MS and clinical studies of people with MS that concludes exercise protects and repairs the brain. The reviewers note that while data suggest that exercise improves brain and spinal cord structures and functions, there is still much to learn. Another [study](#) looked at physical fitness in youth with MS, and its relationship to disease activity. Data showed that youth subjects with MS had lower levels of physical fitness in general, compared with healthy controls. Those that did moderate or vigorous exercise had less disease activity and disability.



MS is at least two to three times more common in women than men. There is [mounting evidence](#) that the female hormones, such as estrogen and progesterone, not only affect the reproductive system, but also the nervous and immune systems. In February, [investigators](#) at the University of California, Riverside, reported that treatment with an estrogen-like compound, called indazole chloride, repaired damage to myelin, protected nerve fibers from damage, and partially restored visual function in mice with an MS-like disease. It's important

to note that estrogens impact the reproductive system and have been linked to cancers. Further study is required to determine if such a treatment would be safe and effective for people with MS. Another interesting [study](#) of nearly 3,000 women with MS concluded that most of the complications associated with pregnancy (preeclampsia, gestational diabetes, placenta complications, emergency c-section, instrumental delivery, stillbirth, premature birth, infants with congenital malformations or low Apgar score) are not more likely in women with MS. Data suggest that women with MS were more likely to have elective c-sections, induced delivery, and babies that were small for their gestational age, than women without MS. The use of DMTs did not significantly impact birth weight. It's important to note that this study did not collect information on smoking status, which can impact birth weights.

Advancements in research are continually shedding light on what causes MS (or makes it more likely), discovering factors that impact the disease course, and revealing new treatment strategies. This new knowledge helps to improve the health and quality of life for many people who live with the disease and is moving us closer to finding a cure. The core of ACP's mission is to facilitate research efforts like these, that significantly impact the MS community.



## Emily and Oscar's Powerful Mission

[Pediatric MS](#) isn't common. According to a [2020 literature review](#), it affects approximately 2 to 10 percent of people with the disease. Nevertheless, when a child or teen is diagnosed with MS, the entire family is significantly impacted. A minor with the disease may struggle with disability, which often takes an emotional toll and has social implications at a time when relationships are typically of utmost importance. This, in turn, affects family members as they watch their loved one cope. The vast majority of MS research focuses on the adult MS population. Further study is needed to better understand the safety and effectiveness of MS treatments in this age group, the overall impact of pediatric MS and determine the best ways to help families affected by the disease. Resilience, strength and compassion all ring true in one amazing young lady who has graciously navigated the challenges of MS as a teen. She is now following her heart and using her insight and networking skills to directly help others walking a similar path. She is also joining in ACP's efforts to expand MS research to better understand their journey.



Emily Blosberg's father was diagnosed with MS in 1998, when she was 2 years old. In the summer of 2010, when her family went on a road trip to Washington DC, Emily struggled with the heat more than her father. Her parents found that odd, but figured she just wasn't drinking enough water. A few months later, she noticed a sensation in her right hand, like she was wearing a glove (and she wasn't) and this sensation spread to her entire body. Her skin became so sensitive that wearing clothing hurt. She experienced a number of other puzzling symptoms over the next 14 months, including loss of balance, problems with her vision, fatigue, and headaches. Emily spent much of 8<sup>th</sup> grade going to doctor's visits, physical and occupational therapy. She was diagnosed with MS in November 2011, when she was 15 years old. High school was a challenge as Emily was only able to attend half of her classes in person. However, her dad was a strong role model on how to live life with MS and not let it get in the way. She completed the rest of her classes independently in order to graduate on time with her class and recently graduated from college with a degree in Communications.

When Emily learned of her MS diagnosis, she blamed herself. She shares, "I was getting a lot of attention. People were sending me cards and gifts. I basically had my mom's undivided attention for an entire year. I was honestly enjoying it... When I started to get

better, part of me wished that something would happen so I could get that attention again.” Emily’s support system is largely her family. In her words, “Before my diagnosis I had some very strong friends in middle school. Afterward they all sort of trickled off. I wasn’t in school, they weren’t seeing me very often and they all continued doing their own thing.” Emily longed to meet other teenagers with MS. About a year after she was diagnosed, she learned of 4 teens with MS in Sioux Falls, SD (all going to the same doctor). Emily connected with the teens on Facebook and, in a group chat, they decided to meet for breakfast one Saturday morning. Emily and her father drove 5 hours to spend the weekend in Sioux Falls. They formed a strong bond that weekend and created a [video](#) with a powerful message, “We’re regular teens, we have MS, we have this thing in common.”

After this momentous weekend, Emily started searching the Internet for teenagers with MS and created a Facebook page for them to meet. She put a map on her bedroom wall. Every time she found a child or a teenager with MS, she added them to the map. She introduced any that were relatively close to each other, so they’d know there was someone else their age with MS nearby. Emily shares, “I didn’t want anyone else to feel that loneliness that I felt. I created that support for other kids because I didn’t want them to feel like they had to search as hard as I did to find it. I want it to be there for them, easy to find so when they do need help, they can find it with the click of a button.” This was the beginning of [Mr. Oscar Monkey](#), a nonprofit organization that supports children and their families on their journey with MS.



Emily is a long-time volunteer for the National MS Society. She states, “As long as I could hold a pom-pom in my hand, I was cheering people on at the finish line of their bike rides and walks.” Emily describes herself as a very “crafty person.” She loves to knit but, when



she was first diagnosed with MS, the feeling of yarn running across her fingers was too painful. Still wanting to do something with her hands, she switched to making sock monkeys and sold quite a few to raise money for the Society. One day she decided to make a sock monkey for

herself out of a pair of orange hunting socks and named it Oscar. She brought Oscar to a number of Society events and eventually created another [Facebook page](#) so people could follow what Oscar was doing. After a couple of months, her followers started asking if Oscar could visit them. In response, Emily created Oscar's Buddies to go out into the world to be a friend to anyone who requested one. Emily sent her first one in December 2015 and has sent almost 500 to families around the world since then. She encourages families to post pictures of themselves with their buddy so others can see that they are part of a community, in hopes of bringing everyone together. Emily shares, "We have some kids that bring their monkey to their doctor appointments. They tell their doctor how their monkey is feeling, which really takes the pressure off of them. They feel safer communicating that way... We've made them MRI-friendly, so they can take them into the MRI machine with them."

Emily stays in tune with the pediatric MS community and creates fellowship opportunities through Mr. Oscar Monkey that help families living with the disease connect across the nation and the world. For the past three years on President's Day weekend,

families have come together at Oscar's Buddy Bash (a family camp) to share a long weekend of fun, fellowship, stories, education, and laughter. Kids with MS, parents and siblings split into groups periodically throughout the weekend for the opportunity to ask each other questions and have relevant discussions. Emily's sister often leads the sibling discussion. In Emily's words, "Recognizing that MS affects the whole family is so important. The parents enjoy being able to get together, ask questions and share with each other. It's important for the siblings to have that connection as well. My sister often faces the guilt of being the healthy child. It helps her to be able to share that with the other siblings and have them understand what it's like to have a sister with MS... Everyone comes as strangers, but it becomes such a tight knit group." Unfortunately, the Buddy Bash was cancelled in 2021 because of the pandemic, but Emily hopes it will be an annual event in the future.





Mr. Oscar Monkey held their first Teen Camp in the summer of 2019, with 25 campers in attendance. Some of them were college-aged kids with MS that served as role models for the younger campers and answered questions about life with MS after high school. Emily shares, “This group of kids truly became a family that week.” Because of the pandemic, Oscar’s teen camp was [virtual](#) in 2020. Emily sent “camp in a box” to 40 campers around the world. Each box contained a Camp Quarantine 2020 t-shirt, postcards for campers to send to each other, a roll of toilet paper, a facemask, Apples to Apples cards, a small painting canvas, a tabletop cornhole game, some snacks and a tealight candle for a campfire. The group had camp over Zoom one night, played Apples to Apples virtually and painted their canvases together.

Emily holds a Zoom call twice a month for teenagers with MS or a similar diagnosis, which has been a wonderful way for campers to stay connected. She states, “We have new kids joining almost every call. We started with just our 25 campers and we now have over 50 attending.” Oscar also hosts weekly calls for kids 12 and under whenever there is a need. Anyone interested can find information on how to join these calls on the Mr. Oscar Monkey [website](#). Half of the campers are high school seniors who, according to Emily, still want to be a part of the Oscar community. In response, Emily is planning a young adult retreat for when the pandemic is over to provide an opportunity for them to continue to connect with each other.



Emily’s goal for 2021 is to start a scholarship fund through Mr. Oscar Monkey, offering fifteen \$1,000 scholarships to high school seniors. She explains, “Many scholarships require students to be registered for a minimum number of credits in order to be eligible...12 credits can be really hard to handle for a student with MS. We want to take that credit requirement away. If you’re registered in a class at college, that’s amazing. You’re continuing your education, you’re working around your MS, we want to support you.”

When asked what her greatest joy is with Mr. Oscar Monkey, Emily states, “Oh my gosh, everything. Every time I talk with the kids, I’m re-energized... One teenager and her

family drove from MI to attend the Buddy Bash in 2019. She was 17 at the time, just diagnosed 4 months before. Her parents were excited about the opportunity to connect with other people, maybe learn a little bit. She was very bitter the whole drive there. By Saturday (the second day) her dad was in tears because he had not seen her smile since she was diagnosed in November. And she was smiling. In 2020, she and her family came back to Buddy Bash and there was a girl her age, newly diagnosed just a couple of months before with a pretty negative outlook on life. The two of them spent time together that weekend and are absolutely best friends now. Things like that motivate me... These kids are my world. I will continue to do everything I can for as long as I can. As long as there are kids that still need it, I'm not going to stop."

With the support of a PCORI Engagement Award, iConquerMS will be expanding enrollment to include children and teens with MS and their loved ones. Through this effort, families will be able to contribute valuable data to shed light on many aspects of living with pediatric MS, help steer the future direction of MS research and may one day play a role in unlocking the answer to a cure. Emily is co-leading this project with ACP's CEO, Sara Loud. In her words, "It's important to create a place that recognizes pediatric MS as a relevant part of our world and makes sure pediatric voices are heard. Recognizing that kids' needs are so different than adults with MS and exploring that more. What can be helpful and what should be done within the pediatric MS community... In my personal opinion, I think kids hold the key to curing MS. If you think about environmental triggers, the number of things a 6-year old has been exposed to is so much smaller than a 35-year old. Even just that little piece. Having research opportunities in pediatrics will benefit the entire MS community."



In closing, Emily shares perspective gained from working with the kids at Mr. Oscar Monkey, "There's a stigma out there and it's a challenge that we face when trying to reach out to kids. Admitting and recognizing that they have MS is a huge challenge for a lot of

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A Research Study  
EVERYONE  
can join!

our kids because they don't want to be sick. Parents will reach out on their child's behalf, but they're not ready yet. It's a lot to digest. If they get involved in something like this, they're admitting that they have the disease." Something to keep in mind in our recruitment efforts moving forward. When asked what advice she

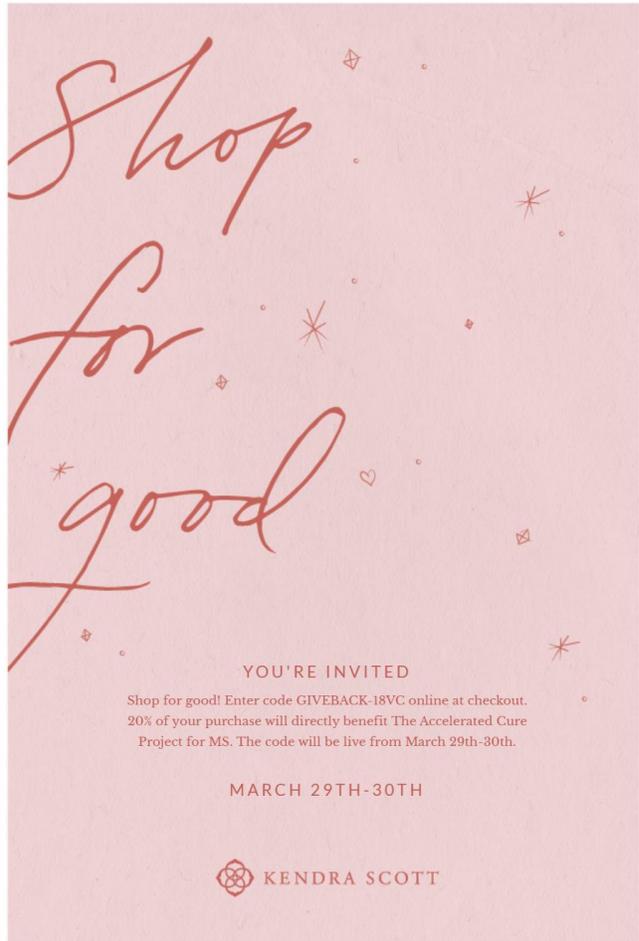
would give to a child or teen that is considering joining the iConquerMS community, Emily said, “I would say join because, first of all, you’re part of a very strong and supportive community, and also you have the potential to help so many other people.” We are grateful for Emily’s advocacy toward the pediatric MS community and her insight as we work toward including this important population in iConquerMS.

## March 2021 Research Spotlight

### EVENTS

#### Shop for good! You're Invited!

Want to treat yourself and help accelerate MS research at the same time? Shop on the [Kendra Scott website](#) March 29<sup>th</sup> to March 30<sup>th</sup> and enter code GIVEBACK-18VC at checkout. Twenty percent of your purchase will directly benefit ACP!



## RESEARCH OPPORTUNITIES



### **New opportunity! Share your experiences with COVID-19 vaccines.**

ACP, through its people-powered research network [iConquerMS](#), is now collecting information from people affected by MS related to their experiences with COVID-19 vaccines. The data collected will be securely shared with researchers studying the effects of COVID-19 vaccination on people affected by MS. 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 start adding your data!

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**UNIVERSITY OF GEORGIA**

### **Researcher studying fatigue in MS would like your help!**

**Have you ever wondered about the connection between physical and emotional aspects of fatigue in MS?**

Fatigue is one of the most frequently reported symptoms in MS, but not enough is known about how tiredness, physical sensations, and emotions lead to feeling fatigued and happen during fatigue.

**You can help understand this important question!**

A PhD student from the University of Georgia who is investigating this topic is inviting people with MS to join her research study. She is looking for people who are physically active, between 18 and 65 years old, and have reliable Internet and phone access.

Participation involves taking a survey online and (optionally) having a phone conversation with the researcher to answer additional questions. The survey will take up to 45 minutes and the optional phone conversation will take an additional 1 hour.

Research study participants will receive a summary of the findings at the end of the study.

**Are you interested in helping with this research study?**

Please contact Megan Ware by email at [mew77577@uga.edu](mailto:mew77577@uga.edu) or by phone at 423-260-5045.

Thank you!



## **Call for Participants with Multiple Sclerosis**

**Have you been diagnosed with multiple sclerosis for 2 years or less?**

**Are you older than 18 years of age?**

If the answers to all these questions are **yes**, investigators at the University of Alabama invite you to take part in a voluntary study 'Social Cognitive Correlates of Physical Activity in Adults with Multiple Sclerosis in the United States.'

### **What will you do?**

You will be asked to complete questionnaires about your health beliefs and physical activity.

### **Why is this research important?**

Previous research reports significant relationships between social cognitive variables such as social support, self-regulation, motivation and physical activity in adults from the general population. This study is a novel investigation of various social cognitive factors that may be associated with levels of physical activity in persons with MS.

### **What's in it for me?**

You will be helping researchers at the University of Alabama by providing invaluable feedback that will be used to help inform future multi-level physical activity interventions for persons with MS.

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If you are interested in completing this survey, please click [this link](#) or email Trinh (Lexi) Huynh at [enrl@uabmc.edu](mailto:enrl@uabmc.edu).

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## New Year, New You

**Study Title:** Step for MS (Supervised versus Telerehab Exercise Program for People with Multiple Sclerosis)

### **Study Purpose:**

New research shows that exercise is good for people with MS and may decrease symptoms and improve health and walking ability. An exercise study called *STEP for MS* will compare the outcomes of a 16-week exercise program conducted at home to a program conducted in a gym. The researchers conducting the study hope that the findings will make exercise and its benefits more available to people with MS who have problems walking.

### **This Study Involves:**

Participants will exercise two times per week for about one hour each session for 16 weeks. A trained “coach” will help participants learn how to exercise and will provide encouragement throughout the program. Participants will take assessments before starting the program, two months into the program, at 16-weeks when the program ends, and at 6 and 12 months after starting the program.

### **Eligibility:**

If you are between the ages of 18 and 65 years and you have Multiple Sclerosis you may qualify if you:

- Can **walk** but you have **some difficulty**, with or without a device
- **Do not exercise** regularly
- Have not had a **relapse** in the past month
- Can commit to **train 2 times a week for 16 weeks**

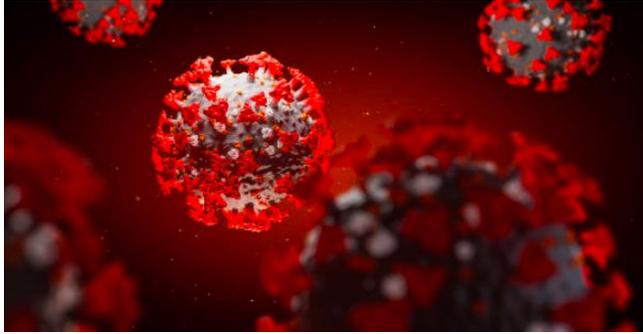
- Can **drive to study site** for assessments and potentially for exercise training
- Have reliable **internet access**

### **Participating Locations:**

- Massachusetts General Hospital, Boston, MA (**new site now open!**)  
**Contact:** Dr. Plumer 617-724-3103/ [PPlummer@MGHIHP.EDU](mailto:PPlummer@MGHIHP.EDU)
- Shepherd Center, Atlanta, GA  
**Contact:** Erica Sutton at 404-367-1305
- Cleveland Clinic, Mellen Center, Cleveland, OH  
**Contact:** Darlene Stough at 216-445-5877/ [stoughd@ccf.org](mailto:stoughd@ccf.org)
- University of Colorado, Denver  
**Contact:** Alexa Vareldzis: [neurologyresearchpartners@cuanschutz.edu](mailto:neurologyresearchpartners@cuanschutz.edu) / 303-724-4644
- University of Alabama, Birmingham  
**Contact:** Petra Silic at 205-975-1306/ [petra09@uab.edu](mailto:petra09@uab.edu)
- University of Georgia, Athens  
**Contact:** Megan Ware at 423-260-5045/ [megan.ware20@uga.edu](mailto:megan.ware20@uga.edu)
- Marquette University, Milwaukee, WI  
**Contact:** Heidi Feuling at 414-288-6209/ [Heidi.feuling@marquette.edu](mailto:Heidi.feuling@marquette.edu)
- University of North Carolina, Chapel Hill  
**Contact:** Rachel Keen at 704-877-5636/ [rayray@live.unc.edu](mailto:rayray@live.unc.edu)

For more information, please visit our

website: <https://www.iconquerms.org/welcome-step-ms>



## **Update your experience with COVID-19**

As a supporter of Accelerated Cure Project, you know one way to deal with the uncertainty of MS is to **act** – to be proactively involved in research and to contribute your insights, expertise, and information so that key questions about MS may be answered.

The COVID-19 crisis has added an additional level of complexity and urgency for those affected by MS.

**We have launched a follow-up survey on iConquerMS to update how people affected by MS are dealing with the COVID-19 pandemic and what their personal experience has been with COVID-19 over the past 12 months.**

**We are interested in responses from all – those with and without MS, whether or not you have been diagnosed with COVID-19 – and hope the information gathered through this survey will help people affected by MS and their doctors during the current pandemic and in the case of future viral outbreaks.**

Participating in the COVID-19 in MS study is easy. If you are not already a member, please consider [joining iConquerMS](#). Your voice matters! Already a member? Please [login](#) to your account and complete your COVID-19 survey. Thank you for your participation!

# NEW RESEARCH RESULTS



## **Making Strides to Diversify MS Research**

The [MS Minority Research Engagement Partnership Network](#) is a team led by ACP that is dedicated to understanding the barriers that prevent minorities from participating in MS research, with the ultimate goal of overcoming them. Network members designed and implemented a survey of people with MS from diverse backgrounds about their research experience and opinions, the [results](#) of which have been published in the International Journal of MS Care. These findings shed light on the concerns that investigators must address in order to recruit a diverse population of subjects in their studies. This is necessary to ensure that the study's benefit applies to everyone, regardless of race or ethnicity.

## March 2021 iConquerMS Spotlight

### Announcing a New Program for iConquerMS Members!

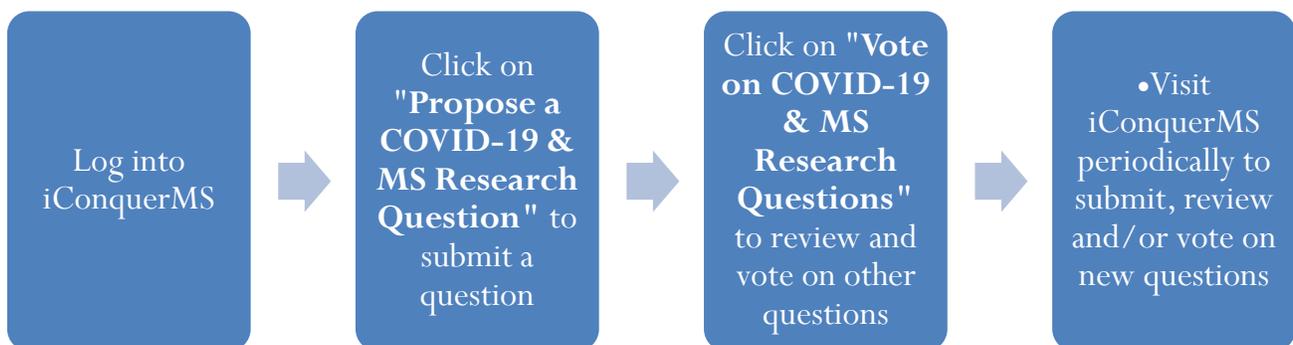
In the past, most clinical research has been “investigator-driven” where the idea for the research topic to be studied comes from a researcher or scientist. Participant driven research (PDR) is research based on questions proposed and prioritized by people affected by a disease or medical condition.



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, 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!