

March 2021 Newsletter



March 2021 Research Spotlight

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!



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 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.

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



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:

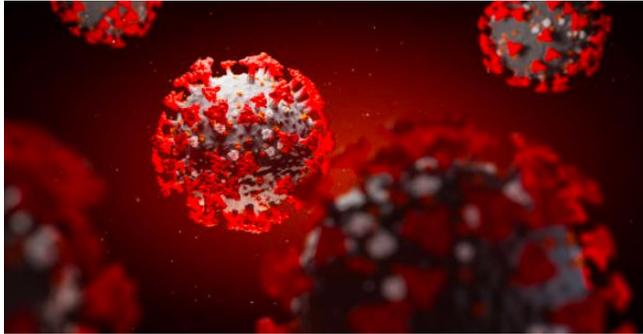
- Can **walk** but you have **some difficulty**, with or without a device
- **Do not exercise** regularly
- Have not had a **relapse** in the past month
- Can commit to **train 2 times a week for 16 weeks**
- Can **drive to study site** for assessments and potentially for exercise training
- Have reliable **internet access**

Participating Locations:

- Massachusetts General Hospital, Boston, MA (**new site now open!**)
Contact: Dr. Plumer 617-724-3103/ PPlummer@MGHIHP.EDU
- 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
- University of Colorado, Denver
Contact: Alexa Vareldzis: neurologyresearchpartners@cuanschutz.edu / 303-724-4644
- University of Alabama, Birmingham
Contact: Petra Silic at 205-975-1306/ petra09@uab.edu
- University of Georgia, Athens
Contact: Megan Ware at 423-260-5045/ megan.ware20@uga.edu
- Marquette University, Milwaukee, WI
Contact: Heidi Feuling at 414-288-6209/ Heidi.feuling@marquette.edu
- University of North Carolina, Chapel Hill
Contact: Rachel Keen at 704-877-5636/ 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.