

# January 2021 Newsletter



## January 2021 Research Spotlight

### EVENTS



### People Powered MS Research With CEO of ACP, Sara Loud

[RealTalk MS](#) is a weekly podcast well worth listening to for anyone who is affected by MS. Hosted by Jon Strum, it provides a platform to stay up to date on the latest information about MS. Jon packs a wealth of information into each 30-minute podcast. He covers a wide range of topics, from groundbreaking MS research to legislation surrounding healthcare issues. Sara Loud, CEO of ACP, is featured on the first episode of the New Year. [Tune in](#) to learn more about iConquerMS and hear how the initiative is

contributing to the expansion of MS research to include and amplify the voices of people affected by the disease. If you're not already a member, please consider [joining iConquerMS](#) to add your voice to MS research. People-powered MS research ensures people affected by MS drive, shape, and accelerate research on topics that matter most to them. It can't happen without *your* participation!

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## RESEARCH OPPORTUNITIES



### **Coming Soon! Share your experiences with COVID-19 vaccines.**

ACP, through its people-powered research network [iConquerMS](#), will soon begin 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. Already a member of iConquerMS? You'll be the first to know when the survey is launched! Not yet a member? Please [join](#) iConquerMS now and stay tuned! In the meantime, please share your experiences related to the pandemic through the newly launched *COVID-19 Recent Experiences* survey [now available](#) on iConquerMS!

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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!

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## **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](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**

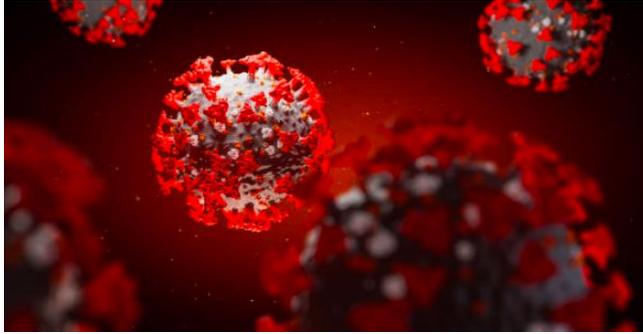
## Participating Locations:

- 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>

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## **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 10 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!