

# December 2020 Newsletter



## December 2020 Research Spotlight

### 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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## **What kind of psychological support would you like for living with MS?**

**Please read on for an invitation from investigators at the University of Reading to participate in one of their studies.**

Psychological and medical literature suggests that people with MS are more prone to mental health problems which highlights the need for such services to be made available for this population. There are different types of support available to people with MS, however not all are accessible or suitable to match the varying needs of people living with the disease.

Over the next 18 months our research aims to develop a psychological intervention that is tailored for people with MS. We are inviting you to help us in this endeavor by completing a survey. We are asking individuals living with MS about their experiences of accessing support (positive and negative), and their opinions about what kind of support would be useful. We will use this information to design a psychological intervention that will reflect the views of the MS community.

To read more about this research and take part in the survey, please go to the [University of Reading website](#) and click the 'start' button at the bottom of the page. Or you can go directly to the survey by clicking [here](#).

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## Real MS™ (Research Engagement About Life with MS)

In the summer of 2016, the iConquerMS initiative launched REAL MS, a longitudinal study of MS. REAL MS participants complete questionnaires online twice each year on a variety of subjects, including health history, diet, exercise and their experience with MS. A **ninth round** of REAL MS surveys are now available through the [iConquerMS portal](#). Completing these surveys is one of the simplest ways you can accelerate MS research. The information collected will play a pivotal role in helping scientists and clinicians gain a better understanding of the health and quality of life over time for people with MS. REAL MS is just one of the many ways iConquerMS is facilitating research on topics of importance to people affected by the disease. If you are not already a member, please consider [joining](#) iConquerMS, the only people-powered research network for MS. Already a member? Please [log in](#) to your account and complete your open surveys!

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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**

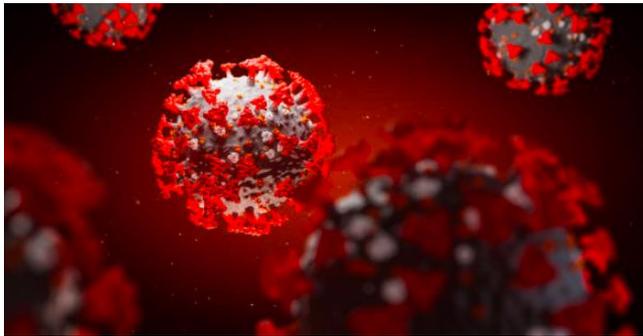
### **Participating Locations:**

- 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 9 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!