

April 2020 Newsletter



April 2020 Research Spotlight

RESEARCH OPPORTUNITIES



**Your health data
has power!**

An invitation to help us learn more about aging with MS

Please read on for an invitation from Cherie Binns, iConquerMS Research Committee co-chair, for network members to participate in a brief (5-minute) [survey](#) related to aging with MS and access to disease modifying therapies and clinical trials. All are invited to [participate](#)! If you are not already a member, please consider [joining iConquerMS](#). Your health data has power!

Hello, fellow members of iConquerMS.

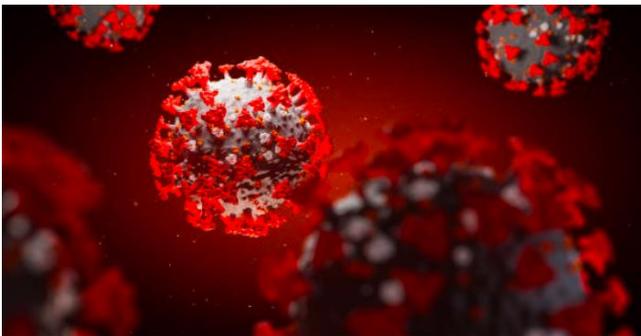
For those of you who have done the REAL MS surveys, you know that there is always an option in those surveys to put forth suggestions about research topics that matter to you. One of those areas of concern that has emerged over the past 3-4 years has been aging with MS.

Some individuals have suggested there may be a bias toward those of us who have MS and are a certain age or older. To gather accurate information and move forward in an appropriate manner, we are inviting everyone, regardless of age, to answer a [few questions](#) about the care you receive and your input on that care. Some of us believe this has the potential to open a whole new aspect of thought and care for all as we aim to gracefully age with a chronic illness.

Thank you!

Cherie C. Binns RN MSCN

Co-Chair of Research Committee (and PwMS)



Share 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.

In response, we have just launched a survey on iConquerMS to learn more about how people affected by MS are dealing with the COVID-19 pandemic and what their personal experience has been with COVID-19.

We are interested in responses from all – those with and without MS – 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!



UsAgainstAlzheimer's

What Matters Most: Caregiving Challenges

Study Purpose:

Living with MS takes a toll on families due to both the intensity of care and long disease progression. This study will help shed light on how caregiving affects one's health and quality of life. We've partnered with a sister organization supporting families coping with Alzheimer's disease on a survey about the challenges and concerns of providing care to a

loved one with MS. We will use what we learn to create new materials to educate caregivers about best practices, and resources for caregiving and self-care.

This Study Involves:

This study involves completing an anonymous survey. We'll use these data to better inform care practices and health care provider education. Let us know your biggest challenges, what resources or services you use or wish you had. What advice would you share with other caregivers?

Study Contact Information:

If you're interested in participating in this study, you can access the survey [here](#). Thank you for helping us make life better for all caregivers and their loved ones with MS!

iConquerMS™

A Research Study
EVERYONE
can join!

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. An eighth 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!



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 for the New Year!)
Contact: Dr. Plummer 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>