

# December 2019 Newsletter



## December 2019 Research Spotlight

### EVENTS



## The MS Research Mythbusting Webinar is now Available Online!

While MS affects all races and ethnicities, minority populations may bear an unequal burden from the disease, including a higher risk of aggressive disease and disability. However, minority populations are severely underrepresented in scientific research. In fact, recent studies show that African Americans make up more than 13 percent of the U.S. population but only 5 percent of clinical trial participants and Hispanics, who make up 16 percent of the population account for only 1 percent of research participants.

To help raise awareness and address the misconceptions people often have about research participation in MS, the Multiple Sclerosis Association of America (MSAA) and ACP presented a national webinar, MS Research Mythbusting, on Tuesday, October 29, 2019. MS expert neurologist Mitzi Joi Williams, MD discussed the role research plays in improving the health and well-being of people affected by MS, and the reasons why participation from minority populations is needed to develop treatments for all affected by the disease.

Did you miss MS Research Mythbusting and would you like to see it? Were you able to attend and would you like to see the program again? The webinar is now archived on the MSAA website. Anyone interested in watching it can click [here](#). This program is made possible through educational grants from Genentech and Biogen.

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## RESEARCH OPPORTUNITIES



### A Study to Understand Exercise Behavior in People with MS

**Study Title:** Social Cognitive Correlates of Physical Activity in Adults with Multiple Sclerosis in the United States.

**Study Purpose:**

Social cognition focuses on the role that thought processes play in our social interactions. Previous research suggests cognitive processes like social support, self-regulation and motivation significantly impact physical activity in adults in the general population. This study will evaluate various social cognitive factors that may be associated with exercise behavior in people with MS.

**This study involves:**

This study involves completing a questionnaire about your physical activity and health habits. The survey will take 25-40 minutes to finish. If you begin and want to finish later, you are able to save your progress and come back to answer the questions for up to one week. The valuable feedback that you provide will be used to help inform future exercise interventions for people with MS.

**Participating locations:**

The University of Alabama at Birmingham

**Researcher:**

Robert Motl, Ph.D.

**Recruiting:**

Anyone that is 18 years of age or older and has been diagnosed with MS is welcome to participate in this study. We hope that 1000 people across the United States will complete these questionnaires. Participation in this study is completely voluntary.

**Study website:**

If you are interested in participating in this study, please click [here](#), or e-mail Stephanie Silveira at [enrl@uabmc.edu](mailto:enrl@uabmc.edu).

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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.

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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## A Study to Help Improve MS Clinical Trials

### **Study Purpose:**

A pharmaceutical company (Sponsor) is conducting patient interviews with MS pediatric patients (10 - 17 years old) and their caregivers. The Sponsor will use the information collected during these interviews to improve the overall experience in clinical trials for MS pediatric patients and their caregivers.

### **This Study Involves:**

These interviews will last at most 1 hour and will be conducted by an independent healthcare communications company, AXON Clinical Trial Services (AXON), on behalf of the Sponsor. AXON will share the information provided during the interviews with the

Sponsor in an anonymized manner. This means that it will not include the name or any other personal information that could be used to identify the participants. The information provided will be used to write a report. During the interviews, MS patients and caregivers will be asked about what it is like to live with MS and about their perceptions of clinical trials. Participants will be compensated.

**Study Contact Information:**

If you're interested in participating in this study, please email [MSPeds@axon-com.com](mailto:MSPeds@axon-com.com), or call (416) 848-1464.

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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 for the New Year!)  
**Contact:** Dr. Plumer at 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>