

January 2020 Newsletter



January 2020 Research Spotlight

RESEARCH OPPORTUNITIES



Patient Satisfaction Questionnaire: Clinical Research

Study Purpose:

The Accelerated Cure Project, along with two other patient advocacy groups, is helping with a survey led by Firma Clinical, a company that provides clinical research services including in-home visits. The goal of the survey is to provide patient opinions and preferences regarding clinical trial participation to the pharmaceutical

companies that plan and carry out these trials. The results may help to enhance the patient experience and involvement in drug development in the future.

This study involves:

This study involves completing a short, anonymous survey about participating in clinical trials. Study results and summary will be provided to ACP for sharing with members of the ACP and iConquerMS communities. This research is not sponsored by any pharmaceutical company and they will not have access to any raw data.

Participating locations:

This survey is being conducted under approval by the Institutional Review Board at the University of North Carolina – Wilmington.

Researcher: Firma Clinical

Recruiting: All people with MS, including those who have participated in clinical trials in the past and those who have not.

Contact information/Study website:

To participate in this study, please click the following link. Thanks in advance for your input! <https://www.surveymonkey.com/r/7QRZGT8>



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@cuanchutz.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>



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.



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 MSPed@axon-com.com, or call (416) 848-1464.