

November 2020 Newsletter



November 2020 Research Spotlight

EVENTS



A New Podcast Series for People with MS

EMD Serono, in collaboration with Accelerated Cure Project, has released a 5-part educational podcast series, hosted by Jon Strum, called “Uncovering Sex in MS: A Dialogue About Sex, Parenthood and Hormones.” The topics covered in the podcast series were developed based on input from the [iConquerMS](#) community – another example of how iConquerMS members are driving and shaping MS research and care!

Women are nearly 3 times more likely to develop MS than men. Because the majority of these women are diagnosed during their childbearing years, clinicians and patients are encouraged to incorporate family-planning discussions into their ongoing MS management conversations. Optimal patient care involves coordination among a woman's neurologist, obstetrician/gynecologist, and primary care provider to ensure alignment on the woman's individual family-planning choices and preferences.

[Episode 1](#) features 3 unique perspectives on preconception planning for women with MS: Dr. Lori Travis, a neurologist who specializes in treating patients with MS; Dr. Erkan Buyuk, a reproductive endocrinologist, and Ms. Shannon Green, a pregnant woman living with MS.

Family planning is not just a concern for women with MS. Men with MS also need to be involved in these discussions. They have different concerns about fertility and pregnancy than women with MS. Thus, optimal MS care involves coordination and communication among a man's neurologist and other care team members, such as reproductive endocrinologists and urologists.

[Episode 2](#) features 3 unique perspectives on preconception planning for men with MS: Dr. Lori Travis, a neurologist who specializes in treating patients with MS; Dr. David Ryley, a reproductive endocrinologist with experience in treating men with MS; and Mr. Josh Evitt, a person living with MS who has experienced fertility concerns during the family-planning process.

For pregnant women with MS, preparing for the birth of a child can be a time of excitement and anxiety. Each woman should work closely with her neurologist and other care team members to determine how best to manage her MS in the postpartum period. In addition to postpartum disease management, postpartum depression should also be assessed, because although the data are limited, it appears that new mothers with MS may have an increased risk of postpartum depression.

[Episode 3](#) features 3 unique perspectives on postpartum planning for new mothers with MS: Ms. Melanie Huff, a nurse practitioner who specializes in MS; Dr. Adam Kaplin, a mental health specialist; and Lindsey, a mother with MS who has first-hand experience with the postpartum period.

Up to 90% of men with MS and up to 85% of women with MS will experience at least one form of sexual dysfunction, a higher prevalence than that of the general population. Whether the goal is to have biological children or a simple desire for intimacy and a healthy sex life, sexual dysfunction can take a toll on the physical and emotional aspects of a person's quality of life.

[Episode 4](#) features 3 unique perspectives on how neurologists and patients can recognize and address concerns regarding sexual dysfunction: Dr. Barbara Green, a neurologist specializing in MS, and 2 people with MS, Brooke and Jim, both of whom have experienced sexual dysfunction.

Most patients with MS are diagnosed in early adulthood and live most of their lives with the disease. Various age-related changes can affect the disease course of MS over time. Sex hormones, including estradiol and testosterone, have been found to have neuroprotective effects. These hormones often decrease in patients as they approach their 50s, potentially impacting the disease course in patients with MS.

[Episode 5](#) features 3 unique perspectives on the effects of sex-hormone changes and age-related hormonal changes on the MS disease course: Ms. Amy Perrin Ross, an advanced practice nurse specializing in MS; and 2 people with MS, Mr. Dan Melfi and Ms. Kathey Carr, who discuss how these age-related hormonal changes have affected their disease and overall quality of life.

RESEARCH OPPORTUNITIES



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](#).



Interviews with People Taking Vumerity®: Understanding Your Treatment Experience

Researchers are seeking 20 people in the U.S. with relapsing forms of Multiple Sclerosis including clinically isolated syndrome (CIS), relapsing-remitting multiple sclerosis (RRMS), and active secondary progressive disease (SPMS) to participate in a 1-hour telephone/online interview. The purpose of the interview is to gain insights from people about their experience when taking Vumerity® treatment. The results from this research will be used to gain a better understanding of patients' experiences with Vumerity® and inform how to better support current and future MS patients

Participants must have taken Vumerity® for at least 5 weeks within the past 6 months; participants may currently be taking Vumerity® or may have discontinued Vumerity® within the past 6 months.

If you are interested and meet these criteria, please submit your information here:

https://www.research.net/r/InterviewOp_AcelCure

(Copy this link into your browser if the link does not work)

All participants who complete the 1-hour interview will be compensated. Participation is strictly voluntary, and your responses will remain anonymous.

Endeavour provides research opportunities to patients, caregivers, and healthcare providers, helping organizations who research and develop therapies. By participating in research, your experiences, perspectives, and opinions help researchers better understand diseases and treatment effects from your point of view. For information about our privacy policy, visit <http://endeavour-clinical.com/privacy/>. For questions regarding this opportunity, email research@endeavour-clinical.com.



Share your MS Clinical Trial Experience

A research team based at Johns Hopkins University is looking to interview adults who have multiple sclerosis (MS), and who have experience with clinical trials as part of their treatment. The aim of this research is to improve the understanding of people's experiences living with multiple sclerosis and their participation in clinical trials. The project's goal is to create a web-based resource to support and inform other people who have this condition and who are considering participating in a clinical trial as part of their treatment for multiple sclerosis, as well as their families, friends, health care professionals, and many other audiences. A module will be created on the Health Experiences USA website: <https://healthexperiencesusa.org/>. Participants will partake in an interview about their experience living with multiple sclerosis, diagnosis, treatment, and participation in MS clinical trials. Interviews will last approximately 2 hours, and you will be eligible for a \$50 gift card.

You can participate in the study if you:

- 1) have been diagnosed with multiple sclerosis, and
- 2) were diagnosed at least 1 year ago, and
- 3) have completed, dropped out, or declined to participate in a clinical trial, and
- 4) can comply with all study procedures and are available for the duration of the study

If you are interested, please complete the study's quick eligibility survey here https://jhsph.co1.qualtrics.com/jfe/form/SV_6Vby6gNKY1gYVRH. If you are eligible for the study, a member of the research team will contact you to discuss the study and the possibility of your participation. You can also directly contact the study team via text or call (443) 863-9990, or email healthexperiences@jhu.edu, with any questions or concerns, and someone from the research team will contact you.



Call for Older Adults with Multiple Sclerosis

Are you 60 years or older and living with MS? Are you interested in receiving the HALT MS Research Center Newsletters? Do you want to know more about our events, research activities and findings, or general information about healthy aging and MS?

If the answers to these questions are **yes**, researchers at the University of Alabama at Birmingham (UAB) invite you to take part in the HALT MS Registry.

What will you do?

You will be asked to register and provide your name and email address.

Why is this registry important?

During the HALT MS Research Center Symposium and Focus group, researchers at UAB learned that people with MS would like to have a channel for learning about our center activities such as new study findings, events, and general news of aging and MS, as examples. To that end, one purpose of this project is to establish a registry as an information dissemination mechanism for the HALT MS Research Center.

What's in it for me?

You will be helping us to build the registry that will be used to help researchers at UAB to communicate our research activities, events, and findings about aging and MS.

Will I be compensated for my time?

No, there will be no compensation for registration.

If you are interested in participating in this registry, **please click the link below or e-mail Trinh Huynh at enrl@uabmc.edu.**

https://uab.co1.qualtrics.com/jfe/form/SV_3RcRnwQVX6iptU9



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!



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
- 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>