July 2020 Research Spotlight

EVENTS

A New Podcast Series for People with MS

EMD Serono, in collaboration with Accelerated Cure Project, has released the first two podcasts in 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 three 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 male patient with MS who has experienced fertility concerns during the family-planning process.

Stay tuned for future episodes!
Do you have access to your own MRIs?

If you’ve been diagnosed with MS, you’ve probably had at least one MRI, if not several. Have you ever received a copy of your MRI files for your own use? We’re interested in knowing and invite you to take a short survey on the topic. The survey has up to 20 questions and is expected to take around 10 minutes to answer. Your answers will be collected anonymously. You can click the link above or go to https://www.surveygizmo.com/s3/5624803/iConquerMS-MRI-Access-Survey to participate.

We’d like to know whether people with MS have access to their own MRI files and if they’re interested in viewing, understanding, and/or sharing their MRIs. This will help us learn whether it might be feasible to conduct future research studies that involve MRIs.

The survey results will be shared with a company called Icometrix. Icometrix has developed software and services that help healthcare providers view, store, and analyze medical images such as MRIs. They would like to know how people with MS feel about viewing their own MRIs and whether they have access to their own image files.

If you have any questions, please email us at info@iconquerms.org. Thank you for your help and your input!

The iConquerMS Team
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 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, 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!
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 caregivers feel about interactions with healthcare providers. Are they included in the healthcare conversation? Are their needs brought up and addressed? We’re conducting this survey in partnership with an organization that supports families coping with dementia. We'll use what we learn to better inform care practices and to improve healthcare provider education.

This Study Involves:
This study involves completing an anonymous survey. Are you a person living with MS? Please forward this email to your caregiver(s) and invite them to take this important survey. Are you a caregiver? Please click the link below to participate.

Study Contact Information:
If you’re interested in participating in this study, you can access a survey here. Thank you for helping us make life better for all caregivers and their loved ones with MS!