August 2020 Research Spotlight

EVENTS

A New Podcast Series for People with MS

EMD Serono, in collaboration with Accelerated Cure Project, has released the first three 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 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 male patient 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.

Stay tuned for future episodes!
RESEARCH OPPORTUNITIES

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
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!