

May 2020 Newsletter



May 2020 Research Spotlight

EVENTS



A New Podcast Series for People with MS

ACP, in collaboration with EMD Serono, will soon release a 5-part non-promotional educational podcast series called "[Uncovering Sex and MS: A Dialogue About Sex, Parenthood and Hormones](#)" which will focus on reproductive and hormonal considerations for people living with MS. Based on the feedback from the iConquerMS community, this series will explore MS patient perspectives on sexual dysfunction, male and female preconception counseling, postpartum planning and menopause/andropause. Each

podcast will be approximately 15-20 minutes in length and will include brief interviews between the host and a person/people living with MS, as well as the host and a health care provider. With each episode, providers of patients will gain insights about getting the most out of their clinical conversations and effectively coordinating specific care situations with relevant specialists. The podcast series will be available through the [ACP website](#) and the [EMD Serono YouTube page](#). Stay tuned for more information!

RESEARCH OPPORTUNITIES



What kind of psychological support would you like for living with MS?

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](#).



**Your health data
has power!**

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.

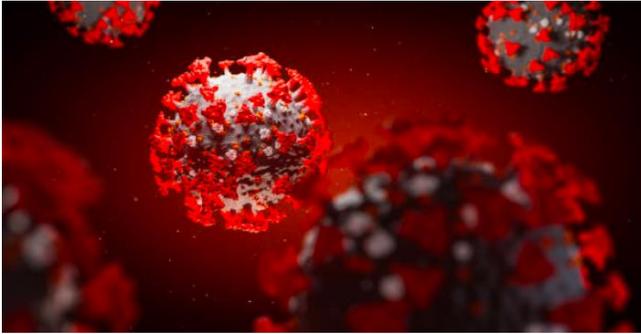
For those of you who have done the REAL MS surveys, you know that there is always an option in those surveys to put forth suggestions about research topics that matter to you. One of those areas of concern that has emerged over the past 3-4 years has been aging with MS.

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 – 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!



UsAgainstAlzheimer's

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 caregiving affects one's health and quality of life. We've partnered with a sister organization supporting families coping with Alzheimer's disease on a survey about the challenges and concerns of providing care to a loved one with MS. We will use what we learn to create new materials to educate caregivers about best practices, and resources for caregiving and self-care.

This Study Involves:

This study involves completing an anonymous survey. We'll use these data to better inform care practices and health care provider education. Let us know your biggest challenges, what resources or services you use or wish you had. What advice would you share with other caregivers?

Study Contact Information:

If you're interested in participating in this study, you can access the survey [here](#). Thank you for helping us make life better for all caregivers and their loved ones with MS!

NEW RESEARCH RESULTS



New predictors in people with MS

Researchers at Case Western Reserve University recently published the results of two studies using data from the ACP Repository.

Depression has a widespread negative impact on outcomes in people with MS, therefore it's important to identify those at risk. The research team's first [paper](#) reveals several factors associated with depression and depression severity in people with MS.

Investigators found having a mother with a history of depression, having obstructive pulmonary disease, obesity and other physical disorders, as well as emotion or mood-related symptoms at MS onset to be strongly associated with depression. Results also show genetic factors associated with the incidence of depression in people with MS. The research team's prediction model is based on easily measured characteristics and could easily be used to decrease the risk of developing depression, as well as identify cases of depression in people with MS.

Predicting the transition from relapsing remitting to secondary progressive MS (SPMS) from early in the disease course is challenging. Investigators at Case Western Reserve University developed a [prediction model](#) for SPMS using clinical measures that would be available at or near MS onset. Results show an older age of MS onset and being male is associated with transitioning to SPMS sooner, and a long interval between an individual's first two relapses predicts a much longer latency. Researchers also found a specific genetic variant (HLA-A*02:01) that is associated with a decreased risk of SPMS. These results have the potential to improve the ability to predict the transition to SPMS using information available at or near disease onset, potentially improving care and quality of life for those who live with MS.