

# June 2020 Newsletter



## June 2020 Research Spotlight

### EVENTS



### A New Podcast Series for People with MS

EMD Serono, in collaboration with Accelerated Cure Project, has released the first of 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. Stay tuned for future episodes!



## **COVID-19 Emergency Food Assistance**

An Emergency Food Assistance Program is available to help those in need during the COVID-19 pandemic. This innovative program is a collaboration between [Team Rubicon](#) (TR) and [Patient Advocate Foundation](#) (PAF) and provides emergency food delivery and financial assistance to people living with cancer, MS, and rheumatoid arthritis. To date this initiative has helped more than 13,000 patients, including 1,000 emergency food deliveries made and over 12,000 financial assistance grants being provided to patients in all 50 states.

### **Who is Eligible?**

Patients with cancer, MS or rheumatoid arthritis who have trouble accessing or affording food or other nutritional needs due to COVID-19, with eligibility established at the point of application in most cases.

## How to Apply and How it Works

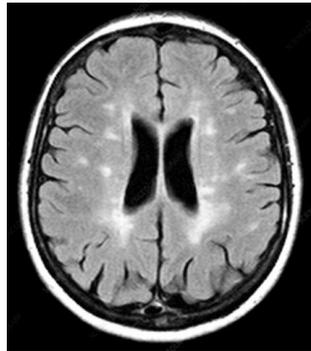
Team Rubicon developed a new feature in its Enterprise Management System (EMS) platform to enable a streamlined, web-based application for patients or their advocates.

Through this process, eligible patients, their caregivers, or care team members can request complimentary delivery of food and other critical supplies directly to their place of residence by one of TR's Greyshirt volunteers. Patients with an identified financial need can apply for a one-time grant of \$300 to help pay for food and nutritional needs, including groceries, food delivery or pick up and medically tailored meals.

For more information, including application instructions, please visit <https://teamrubiconusa.org/applynow>.

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## 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](mailto:info@iconquerms.org). Thank you for your help and your input!

The iConquerMS Team

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## **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](#).

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**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.

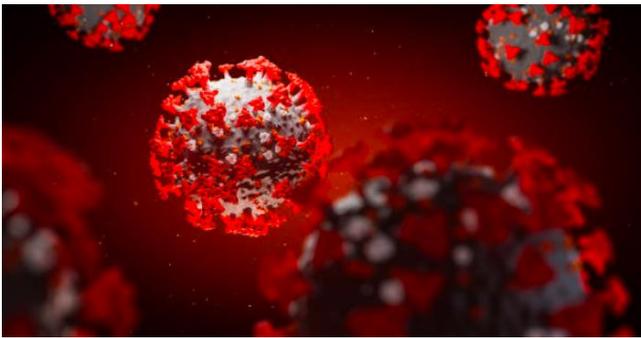
Some individuals have suggested there may be a bias toward those of us who have MS and are a certain age or older. To gather accurate information and move forward in an appropriate manner, we are inviting everyone, regardless of age, to answer a [few questions](#) about the care you receive and your 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)

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### **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!

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**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 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!