

October 2022 Newsletter



October 2022 Research Spotlight

EVENTS



Are you within driving distance of Burlington, Massachusetts?

The wearing of a facemask is requested *but solely at the discretion of each person attending*

11:35am - Guest Speaker: Paul Pelland “Long Haul Paul” - MS Patient Advocate

Listen to this compelling story about this motorcycles’ similarity to MS
→ Entering the World’s Toughest Motorcycle Competition on the most unreliable bike ever built is a lot like everyday life with MS. A painfully humorous and inspiring story of overcoming monumental challenges with ingenuity and sheer will power. - a 35 minute discussion + 5 mins of Q&A



12:15pm – Guest Speaker: Cherie Binns, RN – MS Patient Advocate

Patient Healthcare Liaison at MS FOCUS the Multiple Sclerosis Foundation . Works as Program Presenter at Multiple Sclerosis Foundation and Healthcare Advocate at MS Certified Nurse with Gerontology Degree. Board member with MS Views and News.



→Topic: TRAVELING with a DISABILITY - Includes tips for traveling with physical disabilities and advanced trip planning. - a 40 minute discussion + 30 minute Q&A

1:30pm - Guest Speaker: Lynn Stazzone, A., N.P., M.S. - Brigham Multiple Sclerosis Center

Nurse Practitioner · BSN · MSN Neurological Rehabilitation · Certificate of Advanced Study in Primary Care · Clinical Interests



→ Topics: What Shared Decision Making actually means emerging Therapies, including brand, biosimilars, biologics and generics - a 45 minute discussion + 35 mins of Q&A

Program Date: Saturday, November 19th 2022

Check-in: 10:45 am ET – Program begins at 11:30am ET

With a Complimentary Lunch

****RSVP Required as showing below****

Location: Boston Marriott Burlington

One Burlington Mall Road, Burlington MA. 01803

Please Register (RSVP) Online: www.events.msvn.org

This program is limited to the MS patient plus a (1) guest.

If you do not have Internet, please call (888) 871-1664 – Ext 105

No Walk-ins will be permitted – all must be registered in advance of the event.

This program is supported by:



Exhibitors:



Program provided by MS Views and News, a 501C3 not for profit organization
MS Views and News is **making an impact** on those affected by Multiple Sclerosis
Program to end at approximately 2:55pm



Don't miss our Chat with Chat webinar series!

The Next Steps Committee of iConquerMS has launched a webinar series called “Chat with Chat” and you’re invited! Hosted by our research collaborator Chat Ngorsuraches ([iConquerMS’s newest Ambassador](#)) these conversations provide a glimpse at the researchers working with iConquerMS, what they study, and how their work will benefit people with MS.



In [Episode 1](#), Chat spoke about his own research into the aspects of MS drugs that people value the most.

In [Episode 2](#), Chat spoke with Nina Bozinov, MD MS, about "Measuring the Quality of Life of People With MS: Findings From the REAL MS Study."

In [Episode 3](#), Chat spoke with Farrah Mateen, MD PhD, about what we've learned from iConquerMS about COVID-19 and MS.

In [Episode 4](#), Chat spoke with Farren Briggs, PhD ScM, about “COVID-19 vaccine safety: A study from iConquerMS data.”

In [Episode 5](#), Special guest Hollie Schmidt spoke with Mitch Wallin, MD MPH, about “Telemedicine and MS: Perspectives from Patients and Health Care Providers.”

In [Episode 6](#), Chat spoke with Annabel Decamps from Icometrix, a company that develops software and services that help people view, store, and analyze medical images such as MRIs.

In [Episode 7](#), Chat covers the topic of how (and why!) to become a research accelerator. Hear from people living with MS, researchers, and members of the iConquerMS project team to learn how YOU can accelerate MS research!

In [Episode 8](#), Chat hosted a conversation with Sarah Minden, MD, PhD from Brigham and Women’s Hospital about "Use of complementary and alternative medicine (CAM) by members of iConquerMS".

A heartfelt thank you to Chat and his colleagues for making this educational resource possible. Stay tuned for future episodes!



RESEARCH OPPORTUNITIES

Calling All MS Caregivers!



ACP is working with a small group of MS caregivers and MS professionals (Jon Strum of RealTalk MS, Rosalind Kalb of CanDo MS, and Deborah Miller of the Cleveland Clinic) to develop a “Caregiver Protocol.” The Protocol will be an online compilation of resources to support MS caregivers at all stages of the caregiver journey. We’ve developed a [short survey](#) (5-10 minutes, we promise!) to gather the perspectives of MS caregivers so that their insights can help shape the Protocol. Your input is valuable and much appreciated! Thank you!



New REAL MS Surveys! Sharing Your Experience Matters

New REAL MS surveys have landed on your iConquerMS dashboard! Please [visit the site](#) today and fuel MS research by completing your open surveys.

In addition to accelerating MS research with your data (reason #1!), we'll also be able to tailor upcoming research opportunities for you (reason #2!). Knowing information about your demographics and MS history means that when the right opportunity comes along, we can reach out to YOU!

How to accelerate MS research (and make sure we can contact you with additional research opportunities):

1. Visit your [dashboard](#) (you'll be prompted to log in)
2. Click on the "View and Complete My Research Surveys" button
3. Complete your first open survey
4. Repeat steps 2 and 3 until you have no more open surveys!

If you run into any problems or have any questions, just send us an email at info@iConquerMS.org. Thank you for your participation! Your data – especially your REAL MS data – has power! Your health information is important even if you think things haven't changed much in the last few months.

**Visit My
Dashboard**

Research opportunity information may be provided on behalf of an external organization. Please refer to the contact information within each listing to identify the contact for questions or comments.



Help us understand the benefits of a home-based exercise program for African Americans with MS!

Research opportunity, University of Illinois – Chicago. This study involves the remote delivery of a 16-week exercise training program for rural-residing African-Americans with Multiple Sclerosis (MS).

Benefits of participating

- Learn about methods of improving your health and wellness
- Contribute to ongoing research on African Americans with MS

Eligibility

- MS diagnosis
- Self-identify as African American or Black
- Living in the Southeastern United States
- 18 to 64 years of age
- Internet and email access

For more information:

Contact Edson Flores

(833) 727-1887 enrl@uic.edu



Help Us Make Strides in MS Research!

Who Are We?

MedRhythms is a digital therapeutics company that uses music to improve walking.

How Can You Help?

We are developing a device for individuals with multiple sclerosis to improve mobility. **We are seeking volunteers with MS** to walk with the product and provide feedback.

Interested?

Please email AppliedResearch@medrhythms.com or call (207) 370-2812 to learn more!





You are invited to participate in a research study comparing the effects of three diets!

You are invited to participate in a [research study](#) comparing the effects of three diets – the modified Paleolithic diet (elimination of gluten, dairy, and eggs), a Time Restricted Olive Oil-based Ketogenic diet or your usual diet with information about the USDA Dietary Guidelines for Americans. Participants in the usual diet group will be encouraged but not required to follow the Dietary Guidelines for Americans diet. Quality of life, fatigue, mood, and disease activity will be assessed by online surveys, study participant tasks, & brain imaging. The study will be held at the University of Iowa Hospitals & Clinics over two years. It will consist of three visits to Iowa City, month 0, month 3, & month 24. Each visit can last approximately three and up to six hours.

What you will be asked to do at home while on your assigned study diet

- Follow one of the three study diets randomly assigned to you for 24 months
- Report changes in health and medications
- Eat more non-starchy vegetables
- Eat more home-cooked meals
- Take recommended dietary supplements
- Complete daily food logs (three questions) on a smart phone
- If you are assigned to the ketogenic diet, you must take a blood ketone measurement daily for the first month and then twice a week for the rest of the study
- Complete online surveys

- Watch videos, review study diet guides and meet via Zoom to learn your assigned study diet
- Attend optional online support groups

What you will be asked to do at each of three visits to UIHC

- Complete fasting blood draws
- Complete physical motor skills, cognitive assessment and visual function tasks
- Receive a non-contrast MRI brain scan at first and final end of study UIHC visit (Month 0 and 24)

Requirements to participate

- Diagnosis of relapsing remitting multiple sclerosis (RRMS)
- 18-70 years old
- Able to walk 25 feet without support or unilateral support
- Willingness to adopt any of the three study diets, including the control diet
- Willingness to share medical records for the two years of the study
- Do not have heart disease, liver disease, kidney disease, or type 1 diabetes
- Do not have serious psychiatric disease that would make adopting a study diet more difficult
- Are not taking insulin or coumadin
- Have a smart phone, tablet or iPad to download a free app
- Have access to high-speed internet and a computer or smart phone to participate in video conferences via Zoom and complete online patient surveys
- Commitment to completing surveys for two years and attending the end of study visit

COMMON QUESTIONS

Do I need to live within a specific mile radius of Iowa City?

No, however, if travel funds are needed, we may be able to help. We can offer a travel stipend to support some travel expenses to and from Iowa City. Please speak

with us about your needs. We also offer stipends to participants for attending the site visits and for completing the required online surveys.

Can I pick the diet I want to follow?

We ask that you follow the diet assigned to you. If following your assigned diet becomes difficult contact the study team for assistance.

Can I be in the study if I am in another MS-related study?

If you are in an interventional study investigating drugs, exercise, or other wellness behaviors you cannot be in this study. If you are in an observation-only study, you can still be in this study if you are willing to follow any of the three diets.

If you're interested in taking our screening survey, please visit the link below or scan the QR code with your phone:

⇒ <https://redcap.icts.uiowa.edu/redcap/surveys/?s=JX73EYRJNPF9MHRR>



If you have questions, please contact us at

⇒ MSDietStudy@healthcare.uiowa.edu



**Your health data
has power!**

A new topic for the Our Questions Have Power program!

When it comes to MS symptoms and how to manage them, what questions are most important to you? What symptom-related topics do you wish researchers were studying? **Your questions are valuable** and we invite you to share them through the **Our Questions Have Power** program on the [iConquerMS](#) website.

[The Our Questions Have Power program](#) was launched in March 2021 with an initial focus on COVID-19. Questions submitted by iConquerMS members have helped shape the [COVER-MS vaccination study](#) and are being shared with the research community to guide other efforts.

We're now extending Our Questions Have Power to include a second topic: **MS symptoms and their management and treatment**. As before, you're invited to share questions on this topic that you think should be studied and to vote on questions submitted by other iConquerMS members. We'll share these questions with people affected by MS, researchers, healthcare professionals, advocates, and funders – and, together, we'll work to launch research studies to answer those questions.

It's easy to share your ideas and input in Our Questions Have Power!

Log in to iConquerMS to start (create an account first if you don't already have one).

Click **PROPOSE an MS Research Question** to submit a question you'd like to see studied.

Click **VOTE and COMMENT on MS Research Questions** to review, comment, and vote on questions submitted by other iConquerMS members.