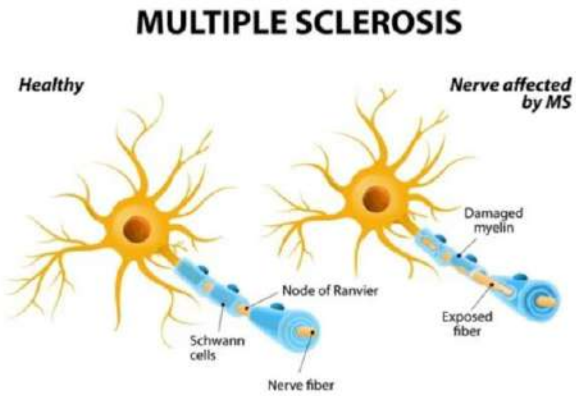
February 2023 Newsletter

Accelerated Cure project for multiple sclerosis
iConquerMS™
ACP Repository™
MS Minority Research Engagement
PARTNERSHIP NETWORK

Does Head Injury Increase the Risk of MS?



MS is an autoimmune disease in which the body's immune system attacks the protective covering of the nerve cells in the central nervous system. This causes communication problems between the brain, spinal cord and the rest of the body. Eventually the disease can cause permanent damage or deterioration of the nerve fibers. The exact cause of MS isn't known, although experts believe that genetics, environmental, and infectious factors play a role in its development. These factors work in different ways and possibly in combination with each other to determine a person's overall risk of developing MS.

MS triggers are different for each person. More than 200 genes have been linked to the disease. Being genetically predisposed to develop MS sets the stage for the disease. There are multiple environmental and infectious factors that have the potential to turn these genes on, such as low vitamin D, smoking, obesity and the Epstein Barr virus. Researchers are exploring whether or not head injuries should be added to this list.

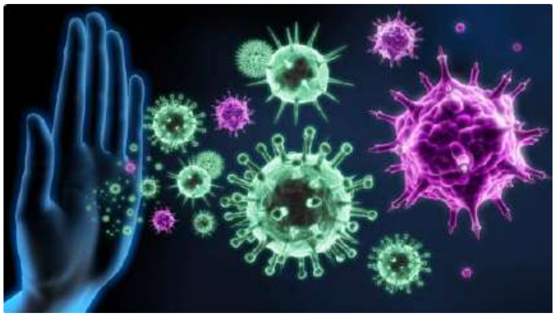
Acquired brain injury (ABI) is a broad term that refers to any type of brain damage that occurs after birth. It can have many different causes, including illness, blows to the head, alcohol and drug use or oxygen deprivation. An ABI that is caused by a blow to the head is referred to as a **traumatic brain injury** (TBI). There are many different types of TBI, with the most common being a **concussion**. A concussion is typically caused by a sudden blow or jolt to the head that makes it move rapidly back and forth. This sudden movement causes the brain to bounce around or twist in the skull, creating chemical changes in the brain and, in some cases, the stretching and damaging of brain cells. Concussion symptoms range from mild to severe and, in some cases, can be long lasting. A contusion often occurs alongside a concussion. A contusion is essentially a bruise on the brain, or a mild form of bleeding. Contusion symptoms depend on its size, location and how long it lasts.

Several studies have explored a possible connection between physical trauma and MS, with conflicting results. A 2008 study looked at more than 150,000 Danish men and women less than 55 years old who had been diagnosed with concussion, brain contusion, or skull fracture and hospitalized from the injury. Researchers determined how many of these people developed MS. They then compared the rate of MS occurring in the head trauma group with people who had MS but no history of head injuries. Data showed no significant statistical difference between the two groups. The researchers concluded that head trauma does not have an effect on a person's risk for developing MS. In 2013, Canadian researchers conducted a review that analyzed published studies from 1950 onward that had explored associations between traumatic injuries and MS. They also found no significant association between any physical trauma and the development of MS. However, the studies included in this review used varying definitions of traumatic injury, ranging from "accidents and burns" to "head trauma with concussion." This makes it difficult to definitively rule out a relationship between head trauma and MS.

A 2014 meta-analysis examined 40 studies into the topic of physical trauma and the risk of MS. Results suggest people who experience head trauma and/or other physical trauma as a child (younger than 20 years) and those who suffer head trauma later in life (older than

20 years) have a higher risk of developing MS. No association was found between spinal injury during childhood, or fractures and burns at any age and the diagnosis of MS. The authors called for further research on the topic to confirm these findings.

More recently, a 2017 study used data from the Swedish National Patient Register and Swedish MS Registry to identify 7,292 individuals with MS. Each person with MS was individually matched by sex, age, and place of residence with 10 people who did not have MS. The team identified any diagnosis of concussion among participants during childhood (between birth and the age of 10 years) and adolescence (between the ages of 11 and 20 years). They found no association between concussion in childhood and the risk of MS in later life. However, results showed that participants who experienced one concussion in adolescence were 22 percent more likely to receive an MS diagnosis later in life, while the risk of MS more than doubled for those who suffered more than one concussion as a teenager. To rule out the possibility that general physical trauma might lead to MS, they also compared broken limb bones between the two groups. There was no connection between broken arms or legs and the risk of MS. It's important to note that these conclusions are based on data from a limited population. Additional studies looking at more diverse groups of subjects are needed to further validate them.



There are several theories for how head trauma could contribute to a person developing MS. There is evidence that a head injury triggers an autoimmune response that impacts the blood-brain barrier. This is the border of cells that lets substances in and out of the central nervous system. If a head injury affects this barrier, substances that are usually blocked could enter the brain and spinal cord, including myelin-attacking cells. Other potential mechanisms through which concussions and other TBIs could lead to the development of MS include damage to the nervous system tissue itself (which may lead to an inappropriate immune response). Head trauma also has the potential to set off a state of inflammation in the brain that could predispose a person to MS.

While there is evidence that head injury may increase the risk of developing MS, there are limitations in the research that has been done to date. Past studies have used different study methods, varying definitions of head trauma and included a limited sector of people. This makes it difficult to make a firm connection between head trauma and MS. More research is needed using consistent parameters and looking at more diverse populations to shed light on this topic, and to determine how trauma might trigger an autoimmune disease like MS. The core of ACP's mission is to facilitate research efforts into topics such as these, which have the potential to improve the health and quality of life for people living with MS throughout their lifetime.

Research Results at Your Fingertips

If you've ever participated in a research study, you know that there's often a lot of communication during the study (reminders about study visits or completing tasks, for example) but things often go very quiet when the study draws to a close. One of the biggest complaints that study participants have is they don't hear about the study's results. Even more generally, there's a lack of information out there for people affected by MS regarding research results and how those results can be used, in collaboration with one's health care providers, to make decisions about living with MS. At ACP, we're committed to changing that!

ACP's iConquerMS is a ground-breaking initiative that empowers people affected by MS to drive MS research and accelerate efforts toward improving treatments and finding a cure for the disease. All of our work is done in partnership with individuals affected by MS. The initiative has a patient-centered governance structure that includes a Governing Board, an Engagement Committee and a Research Committee. The majority of the board and committee members are people affected by MS. These groups work together to oversee the overall policies and direction of iConquerMS, engage people in, and manage research activities done through the initiative.

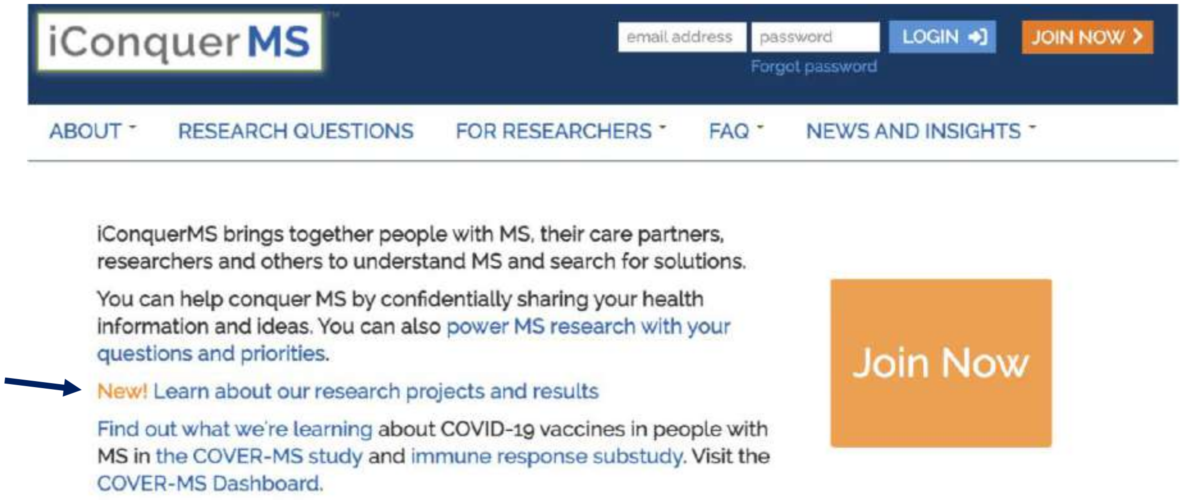
Each November, the iConquerMS governance and other stakeholders in the MS community gather at the iConquerMS Summit to discuss the future direction of the initiative. The dissemination of research results has been a continuing thread at these meetings. In 2021, Summit attendees agreed that iConquerMS should create a plan to make research results readily available in easily understandable language and include this plan in the design of all research done through the network. The consensus was this broad sharing of research findings would positively impact the health and quality of life of the MS community. For iConquerMS, it would not only engage researchers and increase their involvement in the initiative, but also attract people with MS and boost enrollment.

The Next Steps Committee jumped into action to make these ideas a reality. The new Research Projects page on the iConquerMS website is the end result of their hard work. It is a convenient place to track the status of iConquerMS studies (research that network members have contributed to) and review their findings. Summaries of 8 projects are currently listed, and more will be added over time. Some are under development or currently open for participation, while others are completed and have results available to view.

Research projects currently listed:

- Healthcare experiences and disparities in MS
- Impact of COVID-19 and the pandemic on people with MS
- Safety and effectiveness of COVID-19 vaccines in people with MS
- Wellness and diet, MS characteristics and health outcomes
- MRIs in MS: Access, knowledge and interest among people with MS
- Tailoring employment supports for people living with MS
- Use of complementary and alternative medicine by people with MS
- Use of and attitudes toward telemedicine in MS

There are two ways to navigate to the Research Projects page from the [iConquerMS home page](). Users can either click on “Learn about our research projects and results”



iConquerMS brings together people with MS, their care partners, researchers and others to understand MS and search for solutions.

You can help conquer MS by confidentially sharing your health information and ideas. You can also power MS research with your questions and priorities.

New! Learn about our research projects and results

Find out what we're learning about COVID-19 vaccines in people with MS in the COVER-MS study and immune response substudy. Visit the COVER-MS Dashboard.

or hover over “About” on the top left side of the page and click on the submenu “Our Research Projects.”

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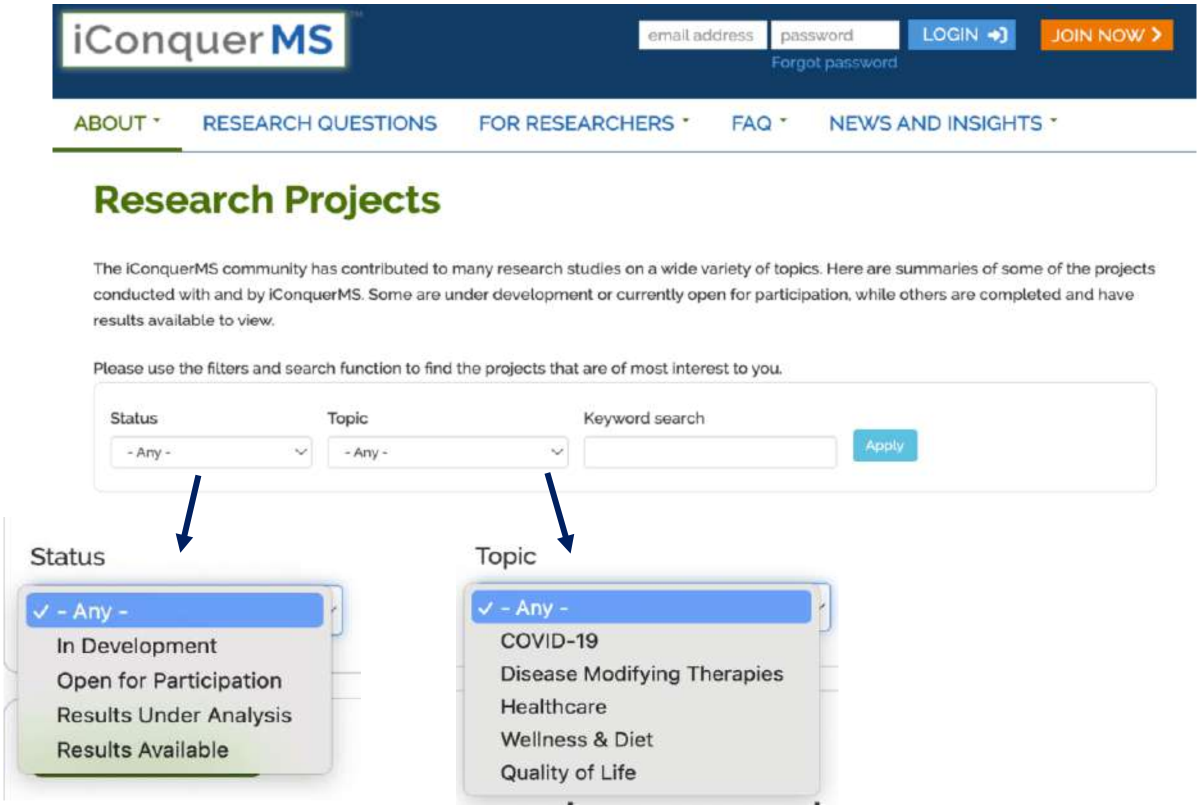
Once on the Research Projects page, one can filter studies by status or topic, or search by keyword to find projects of interest.



Research Projects

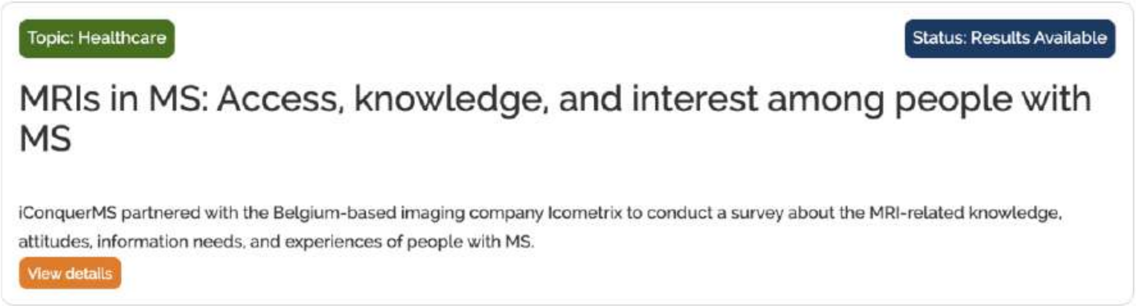
The iConquerMS community has contributed to many research studies on a wide variety of topics. Here are summaries of some of the projects conducted with and by iConquerMS. Some are under development or currently open for participation, while others are completed and have results available to view.

Please use the filters and search function to find the projects that are of most interest to you.

Below these search engines are snapshots of projects enabled by iConquerMS resources. For example, below is a snapshot of a study focusing on MRIs in MS. Users can see at a glance the general research topic, study status and a brief overview of the project.

The “View details” button below each study allows access to more information about the project, including its goals, methods, an interpretation of its findings and next steps.

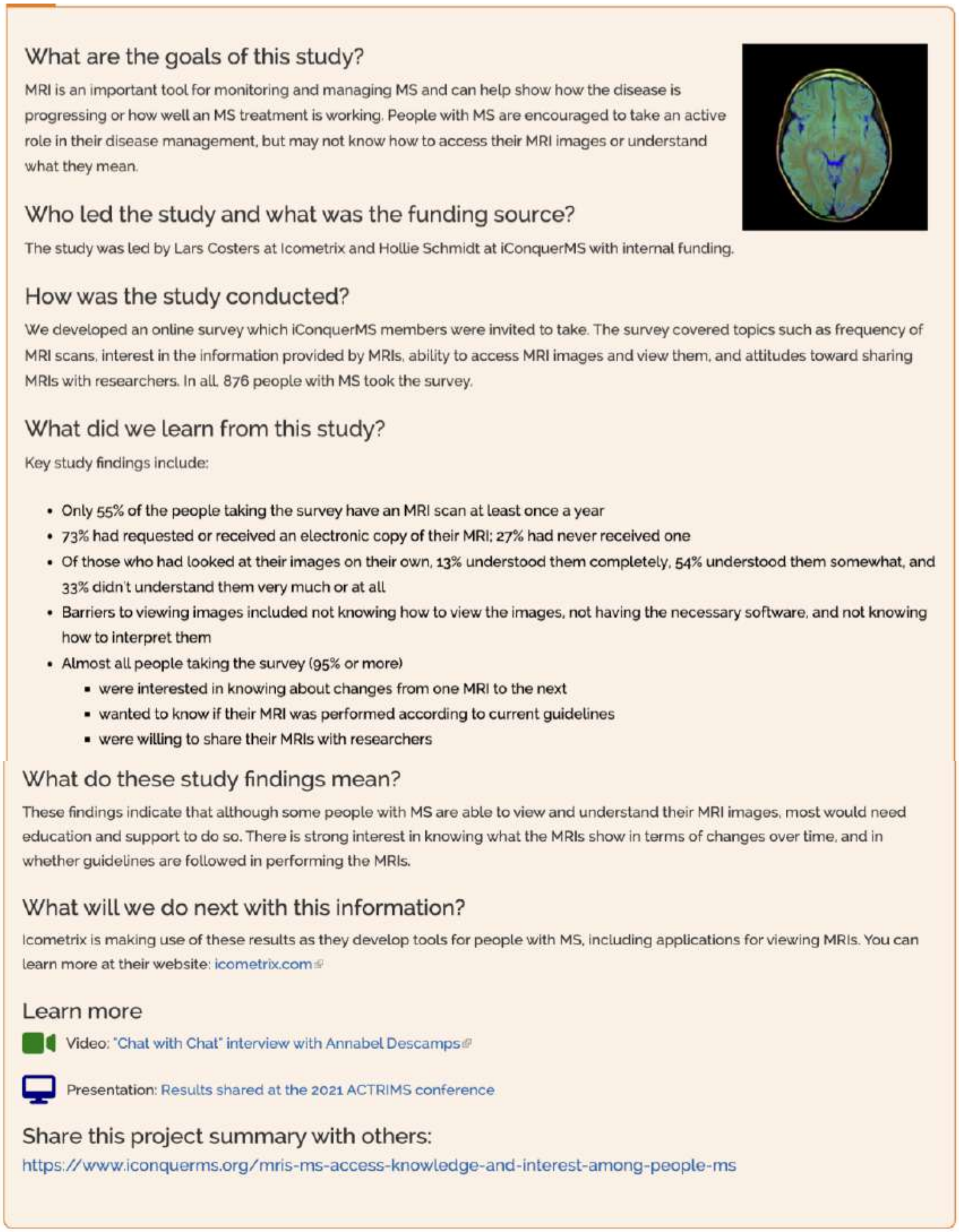
“View Details” Pop-Up Example:



MRIs in MS: Access, knowledge, and interest among people with MS

iConquerMS partnered with the Belgium-based imaging company Icometrix to conduct a survey about the MRI-related knowledge, attitudes, information needs, and experiences of people with MS.

MRIs in MS: Access, knowledge, and interest among people with MS



What are the goals of this study?

MRI is an important tool for monitoring and managing MS and can help show how the disease is progressing or how well an MS treatment is working. People with MS are encouraged to take an active role in their disease management, but may not know how to access their MRI images or understand what they mean.

Who led the study and what was the funding source?

The study was led by Lars Costers at Icometrix and Hollie Schmidt at iConquerMS with internal funding.

How was the study conducted?

We developed an online survey which iConquerMS members were invited to take. The survey covered topics such as frequency of MRI scans, interest in the information provided by MRIs, ability to access MRI images and view them, and attitudes toward sharing MRIs with researchers. In all, 876 people with MS took the survey.

What did we learn from this study?

Key study findings include:

- Only 55% of the people taking the survey have an MRI scan at least once a year
- 73% had requested or received an electronic copy of their MRI; 27% had never received one
- Of those who had looked at their images on their own, 13% understood them completely, 54% understood them somewhat, and 33% didn't understand them very much or at all
- Barriers to viewing images included not knowing how to view the images, not having the necessary software, and not knowing how to interpret them
- Almost all people taking the survey (95% or more)
  - were interested in knowing about changes from one MRI to the next
  - wanted to know if their MRI was performed according to current guidelines
  - were willing to share their MRIs with researchers

What do these study findings mean?

These findings indicate that although some people with MS are able to view and understand their MRI images, most would need education and support to do so. There is strong interest in knowing what the MRIs show in terms of changes over time, and in whether guidelines are followed in performing the MRIs.

What will we do next with this information?

Icometrix is making use of these results as they develop tools for people with MS, including applications for viewing MRIs. You can learn more at their website: icometrix.com

Learn more

Video: "Chat with Chat" interview with Annabel Descamps

Presentation: Results shared at the 2021 ACTRIMS conference

Share this project summary with others:

https://www.iconquerms.org/mris-ms-access-knowledge-and-interest-among-people-ms

The Research Projects page is just one of the many dissemination methods that iConquerMS is using to make MS research results and other resources more accessible to the MS community.

The Chat with Chat webinar series provides a glimpse at the researchers working with iConquerMS, what they study, and how their work will benefit people with MS.

The ACP newsletter is one of the vehicles that provides information about new findings in MS research and much more!

We are proud to partner with RealTalk MS, a weekly podcast that covers a wide range of topics, including groundbreaking MS research.

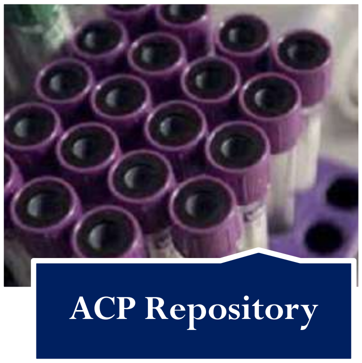
Looking forward, we're in year one of a two year capacity building award to enable iConquerMS to disseminate the results of the PCORI funded MS projects! Stay tuned!

iConquerMS is a collaborative effort between ACP, our partners and the MS community to move MS research toward better treatments and a cure. The Research Projects page was created in response to an expressed desire from network members to stay informed about the studies they have participated in. This online resource was developed with input from our constituents, honoring the way they want to learn and receive information. It is evidence of the breadth of connections iConquerMS is making in the MS community. We look forward to the progress these powerful collaborations will bring in the coming year!

February 2023 Donor's Corner

How do your donations accelerate research for a cure and improve the lives of people affected by MS?

Your generosity supports ACP's initiatives to accelerate MS research for quicker diagnosis, more effective treatments, and a cure for all living with the disease.



If you or a loved one has been diagnosed with MS, you know that living with the disease can bring to mind a lot of questions. Finding answers quickly and in understandable language isn't always easy. Your generosity enables ACP to answer some of these important questions. Thanks to you, ACP is able to provide valuable information about living with MS to those that need it in the MS community.

ACP's Research, Inclusion, Diversity, and Equity Council (RIDE Council), whose members are people with MS belonging to racial, ethnic, and social groups that have been traditionally underrepresented in MS research, have developed resources to address some of the most common challenges that people with MS face:

Learn how to represent yourself so your needs and priorities are at the center of your MS treatment.

Discover ways to connect with peers that have had similar experiences.

Take charge of your health by finding appropriate healthcare professionals for each of your needs.

Read about resources that can help with the financial burden of MS treatment.

Good financial planning can help you maintain control over your treatment path and lifestyle.

Thanks to your support, ACP and iConquerMS can not only accelerate MS research, but also provide valuable information about living with MS to network members and the greater MS community. Join our team and consider making a donation today! Together, we are working to improve the health and quality of life for everyone affected by MS.

February 2023 Research Spotlight

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.

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iConquerMS Spotlight

Want to learn about research that's being done through iConquerMS?

Don't miss the Chat with Chat webinar series!

The Next Steps Committee of iConquerMS has launched a new webinar series called "Chat with Chat" and you're invited! Hosted by our research collaborator Chat Ngorsuraches, these conversations provide a glimpse at the researchers working with iConquerMS, what they study, and how their work will benefit people with MS.

10 episodes of Chat with Chat have aired to date. In case you missed or would like to revisit any of them, they are listed below:

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 spoke with Sarah Minden, MD, PhD from Brigham and Women’s Hospital about "Use of complementary and alternative medicine (CAM) by members of iConquerMS".

In Episode 9, Chat spoke with Nupur Nag, PhD from the University of Melbourne, Australia about “Assessing the impact of lifestyle behaviors on health outcomes in people with MS.”

In Episode 10, Chat spoke with Deborah Miller, PhD, LISW from Cleveland Clinic Lerner College of Medicine about “Insurance coverage for people with MS – where are the gaps?”

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

RESEARCH OPPORTUNITIES

UAB THE UNIVERSITY OF ALABAMA AT BIRMINGHAM

Behavior Change Program for Promoting Physical Activity in Persons Newly Diagnosed with MS

Researchers at the University of Alabama at Birmingham are conducting a behavior change intervention to promote lifestyle physical activity among persons diagnosed with MS within the last 2 years. The researchers aim to examine the effects of the program in helping persons newly diagnosed with MS increase physical activity levels. This study's findings can guide the development of more comprehensive and effective physical activity programs for individuals newly diagnosed with MS.

Participants will take part in a 12-week lifestyle physical activity behavior change program remotely delivered via email and Zoom one-on-one chat sessions. Participants will also complete two assessments of physical activity and MS outcomes before and after the program. All information provided will remain confidential. The researchers are seeking participants who:

- Are 18 years of age or older.
- Diagnosis of MS within the past two years
- Able to walk without assistance
- No relapse within the last 30 days
- Currently physically inactive
- Internet and email access
- Able to read newsletter with a font size of 14 points
- Currently on an MS treatment (DMTs)

Participants will receive compensation of $50 for their time and effort.

If you are interested in participating in this research or would like to learn more about the project, please get in touch with **Lexi Huynh** at **enrl@uabmc.edu**.

Multiple Sclerosis Online Course study

We're Open Again!

JOIN TODAY to receive a **FREE** 6-week online course in March – April 2023: https://www.msonlinecourse.com.au

Module 1 – Introduction to MS

Module 2 – Diet & MS

Module 3 – Sunlight & vitamin D

Module 4 – Exercise & MS

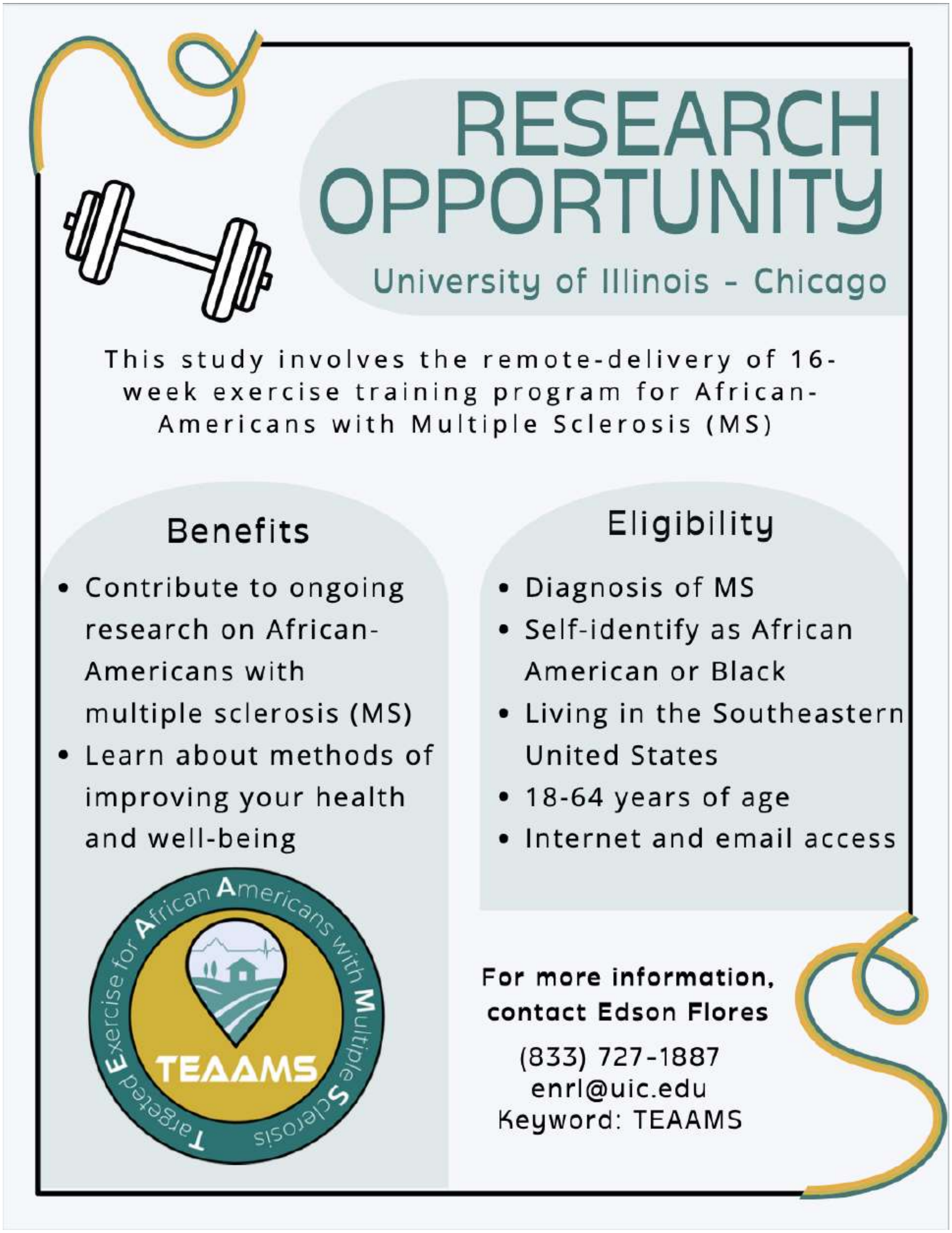
Module 5 – Stress management

Module 6 – Medication & family prevention

Module 7 – Change your life, for life

The course is open to people with MS worldwide, providing you the opportunity to connect with other MSers and play an important role in research to improve how we understand and manage this disease.

Contact Associate Professor Sandra Neate for questions or concerns: neu-research@unimelb.edu.au



RESEARCH OPPORTUNITY

University of Illinois - Chicago

This study involves the remote-delivery of 16-week exercise training program for African-Americans with Multiple Sclerosis (MS)

Benefits

- Contribute to ongoing research on African-Americans with multiple sclerosis (MS)
- Learn about methods of improving your health and well-being

Eligibility

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

Targeted Exercise for African Americans with Multiple Sclerosis

TEAAMS

For more information, contact Edson Flores

(833) 727-1887
enrl@uic.edu
Keyword: TEAAMS

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 attend the of end of study visit

COMMON QUESTIONS

Do I need to live within a specific mile radius of Iowa City?	Can I pick the diet I want to follow?	Can I be in the study if I am in another MS-related study?
No, however, if travel funds are needed, we may be able 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.	We ask that you follow the diet assigned to you. If following your assigned diet becomes difficult contact the study team for assistance.	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**

→ wahls.lab.uiowa.edu/join-study

Changing Medicine.
Changing Lives.®

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!

iConquerMS™

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.