June 2022 Newsletter

Accelerated Cure project for multiple sclerosis

iConquerMS™

ACP Repository™

MS Minority Research Engagement PARTNERSHIP NETWORK

Does Intermittent Fasting Help MS?

A nutritious, well-balanced diet combined with other healthy lifestyle choices is the foundation of good health not only for people with MS, but also for the general public. There is evidence that eating certain foods and nutrients, and avoiding others, may help a person's MS symptoms and disease activity. As we discussed in our August 2019 newsletter, several dietary strategies are being promoted for people with MS, however there is currently insufficient evidence to recommend any of them. Intermittent fasting (IF) is one strategy that has shown promise in mouse models of MS. Researchers are taking a closer look at whether food deprivation may also benefit people living with the disease.

IF is an eating pattern during which an individual switches between periods of normal eating and extreme calorie cutting. It has been around for ages, either because food was scarce and humans had to hunt and gather, or due to religious practices. According to doctrine, Muslims fast from sunrise to sunset during Ramadan and Jewish people fast on Yom Kippur. Hunger strikes have also been used as a form of political protest. More recently, IF has become a popular way to lose weight. It has also been linked with other improvements in health, such as lowering blood pressure, improving blood sugar and lipid levels, repairing damaged cells and protecting brain health.

There are many different types of IF. Each involves not eating (or eating less) during specific hours of the day or specific days of the week.

Types of IF:

5:2	Alternate days	Whole day	Time-restricted	Overnight
• Eat normally 5 days a week and 500 calories or less the other 2 days.	• Eat 500 calories or less every other day.	• Eat just one meal a day and fast for 24 hours between meals.	• Eat only during a set period of time each day and fast for the rest of the day.	• Don't eat for 12 hours overnight (fasting is mostly done while asleep).

How IF might help individuals living with MS is an emerging area of research. A number of studies have looked at the effect of Ramadan fasting in people with MS with mixed results. A 2009 study followed 80 adults with relapsing remitting MS and mild disability for 6 months. Half of the participants fasted during Ramadan and the other half did not. Results showed fasting had no effect on MS disease course over the short term (there were no changes in EDSS as a result of fasting and no difference in the frequency of clinical relapses between the two groups). A 2016 study looked at the effect of Ramadan fasting on 218 people with MS. Results showed there was no beneficial effect on fatigue, however there was a significant improvement in quality of life after fasting. In both studies, investigators state that more research is necessary to confirm their findings.

Researchers at the Washington University School of Medicine (WU) and the University of Connecticut Health Center (UConn) are also studying this eating pattern. Initially, the

team worked with a mouse model of MS, called experimental autoimmune encephalomyelitis (EAE). In this study, some animals were on a fasting regimen, in which they were fed every other day for a period of four weeks. Another set of mice was allowed to eat freely over the same period. All of the mice then received a type of immunization meant to trigger symptoms consistent with MS. Following these steps, all of the rodents continued their respective diet regimens for an additional seven weeks. The researchers found that the mice that fasted every other day were less likely to develop symptoms of neurological damage such as difficulty walking, limb weakness and paralysis. Some of the fasting mice did develop MS-like symptoms, but they appeared later and were less severe than in the mice that ate their fill every day.

Further analysis showed that IF in EAE mice changed blood levels of molecules that relate to inflammation. They had lower levels of pro-inflammatory cells (T helper 17 cells), and higher levels of immune cells that help keep the immune response in check (regulatory T cells). Levels of the anti-inflammatory hormone corticosterone (cortisol) were nearly twice as high in the fasting mice. As discussed in our September 2017 newsletter, the gut microbiome (the collection of microorganisms that live in the intestinal tract) doesn't just help digest food, it also helps regulate the immune system. A change in the type of microorganisms in the gut can alter whether the immune system has a pro- or anti-inflammatory response. Data showed that fasting mice appeared to have a more diverse gut microbiome and higher levels of Lactobacillus, a probiotic bacteria whose abundance in the gut has been linked to less severe MS symptoms. When the researchers transferred gut bacteria collected from the fasting mice to the guts of the non-fasting ones, they noticed that the latter became more resilient to MS-like symptoms.

After these promising results in mice, investigators at WU and UConn conducted a pilot trial of 16 people with MS. Half of the participants followed an IF regimen, which limited their caloric intake every other day for a period of 2 weeks. The other half ate a normal (control) diet. Results showed similar changes in the fasting participants' gut microbiota and immune systems to the ones previously observed in mice. Fasting participants experienced a mild improvement in their Extended Disability Status Scale (EDSS) scores. They also reported an improved quality of life compared to those eating their normal diet. As the trial involved relatively few people and only lasted a short time, it is difficult to draw conclusions about the long-term safety and effectiveness of this type of fasting for people with MS. In addition, it's difficult to determine if the effects seen were due to fasting or the type of food subjects were eating.

To address these issues, the study team conducted a larger clinical trial focusing on IF in 60 people with relapsing-remitting MS. Results are pending. Participants were followed over a 12-week period, half ate a [Western-style diet]() without any alterations and the other half ate the same diet for 5 days and only consumed 500 calories of vegetables the other 2 days each week. All participants continued with their disease modifying therapy and any experiencing a relapse during the study received the necessary treatment. Each participant underwent a neurological assessment and provided blood and stool samples at the start, midpoint and end of the study. These samples are being analyzed to determine if fasting changed the makeup of their gut microbiomes. The researchers are hopeful this study will confirm that IF and the resulting changes to the microbiome are effective at improving MS symptoms in conjunction with other MS treatments. While the prospects for this research are promising, it's important to note that fasting studies have limitations and participant compliance is often an issue. These trials must be tightly controlled and conducted over a sufficient period of time to ensure any effects seen are due to the diet in question.

Sticking to an IF regimen can be a challenge. To stay on track and reap the most benefit, it's important to stay hydrated by drinking lots of water or calorie-free drinks. Eating fruits with high water content, such as grapes or melon, can also help in this regard. Seasoning meals generously may help reduce feelings of hunger. Plan plenty of distractions and avoid strenuous activities on fasting days. Just like with any eating regimen, diet quality while fasting is key. Make every calorie count during the eating window by choosing nutrient-dense foods that are high in fiber, protein and healthy fats (for example, beans, lentils, eggs,

nuts or avocado). This will help to keep blood sugar levels steady and prevent nutritional deficiencies.

IF is considered safe, but it's not right for everyone. It can have unpleasant side effects like hunger, headaches, constipation, bad breath, and fatigue. The combination of low blood sugar levels from fasting and the stress of adjusting to a new routine can also affect one's mood and mental health. Fasting should be done with caution in children and adolescents; athletes; people who are pregnant, trying to become pregnant or breastfeeding; diabetics; or those with a history of eating disorders. Before starting a fast or making any other drastic changes to their diet, people with MS should consult with their healthcare team to ensure that they know how to do so safely. They should also discuss fasting with their pharmacist, as some medications may need to be taken with food to prevent gastric distress or other problems.

Meet Our Newest iConquerMS Ambassador!

iConquerMS would not be possible without people and organizations who care about MS research and conquering MS. The iConquerMS Ambassador Program recognizes individuals that are dedicated to improving the lives of those living with the disease and ultimately finding a cure. It is our pleasure to introduce you to a researcher whose enthusiasm for serving the MS community is inspiring, our newest iConquerMS Ambassador, Surachat Ngorsuraches (Chat).

Chat is originally from Thailand and currently lives in Auburn, AL. He is a faculty member at Auburn University's Harrison College of Pharmacy, where he teaches their Doctor of Pharmacy program and their graduate program in Health Outcomes Research and Policy. His research areas include pharmaceutical economics and policy, focusing on patient preferences and patient-centered research.

As we discussed last month, the National MS Society recently sponsored research to investigate the economic impact of MS. As anyone living with the disease can attest to, their findings confirm that living with MS is very expensive. Dr. Ngorsuraches served on the advisory committee for this project. In his words, "The evidence presented in this paper can be used to advocate for policy changes in the future. Letting the legislature or policy makers know that the economic burden for the patients and families is very high, especially for the cost of DMTs, enables them to work with the pharmaceutical industry or drug manufacturers to try and reduce the cost for the patient. Encouraging policy makers to support more MS research is another way to reduce the economic burden of the disease."

There is a growing recognition of the importance of incorporating the patient perspective into every step of the research and development of new treatments. People living with conditions like MS are often faced with treatment choices in the course of their disease. They are the experts on what it's like to live with chronic illness and the impact of treatments on their quality of life. The patient's point of view can be used to deepen the understanding of living with such conditions. Improving patient engagement throughout the industry and incorporating the patient voice into the design of products and services has great potential to improve patient outcomes which will, in turn, benefit everyone. Chat is a big proponent of patient-centered research. He states, “We like to improve quality of life for people with MS and their families. There are a lot of missing parts in the research that’s been done. These efforts can help people with MS to some degree, but we could do way better if we actually put them at the center of the research and engaged them throughout the research process.”

Chat received funding for two studies from the Patient-Centered Outcomes Research Institute (PCORI), which has also provided funding to ACP for the development and operation of iConquerMS. Both of Chat’s awards are capacity building projects to pave the way for future patient-centered research. In his words, “We work with patients in phases. We start by talking with them about what they need in terms of training or knowledge to get comfortable enough to talk with the researchers or healthcare providers. Then we develop several trainings during which speakers and researchers are invited to spend time and talk with them. During the next phase we ask patients to brainstorm with researchers and healthcare providers to come up with research questions that are important to them. Finally, we discuss how we are going to work together as a research community. This research community is unique. It has to be led by patients or families, not by me or any healthcare provider or researcher, to make sure they have authority and power in terms of the direction they want go.” Chat’s first project enabled the creation of a patient-centered MS research community in the Midwest (North Dakota, South Dakota, Minnesota, Iowa, and Wisconsin). The second project, currently underway, will use resources developed and implemented in the Midwest project to facilitate the formation of a similar group in the Deep South states (Mississippi and Alabama).

Diversity in research is another one of Chat’s main areas of interest. When research involves a group of people who are too much alike, the findings may not apply to or benefit everyone. It’s important for participants in clinical trials to “look like” the patients who could end up taking the treatments. In Chat’s words, “Diversity is critical, especially in pharmaceutical development or treatment development. We know that MS affects underrepresented populations more and differently than the others, but the majority of participants in clinical trials are Caucasian. How can you determine the appropriate treatment and dosing with people who are not in the clinical trial?" From their discussions with participants, Chat and his colleagues have determined that a lack of trust and accessibility are both barriers to participating in research for minorities with MS. He states, "I spoke to a few patients and they mentioned they don't have access to resources or research. Even if they find a study they still need to be at work. You ask them to participate, spend time with research, but they have two or three shifts of work. How is that going to work?" Chat's study team looks forward to finding solutions for minorities that would like to participate in MS research as they learn more and get a clearer picture of the barriers that stand in the way.

Chat has been instrumental in spreading the word about the researchers who are working with iConquerMS through his monthly webinar series "Chat with Chat." He shares, "The MS community has given me the opportunity to learn about them and do my research. This is my way of giving back. We share directly with the community about research that's being done and give them a chance to meet with the researchers, if they want to… We record the webinars and make them available on You Tube." The highlights of being host for Chat include working with the speakers, observing the audience during the webinar and the dialogue afterward. Chat has an exciting lineup of speakers covering a variety of interesting topics in the coming months, including MRI's and brain scans in MS; insurance, disability income and long-term care; and complementary and alternative medicine. Stay tuned!

Chat states that he initially didn't have a personal connection with MS but as he's been working in the MS space for some time, he now has friends living with MS. When asked how he first heard about ACP, Chat replied, "I never knew about MS until 2015. I was writing a proposal for a project for which I needed to reach out to people with MS. My collaborator suggested that I contact ACP for help. I talked to Hollie Schmidt and she was super welcoming and helpful." When asked what about ACP's mission inspires him the most, he shares, "How they can reach out to people and connect. At every Leadership Summit, every time we create a new meeting, there will always be new people. Some people think I am an extrovert, but I'm really an introvert. So, when I see people that can make or expand a network, that amazes me."

Chat is the first researcher to become an iConquerMS Ambassador. He shares, “This means a million dollars to me. I think I have been an informal ambassador forever. My first collaboration was with iConquerMS. For me, iConquerMS is family, they are very special, almost like my parent organization. Whenever they need help or whenever I feel like I can help them, I would not be reluctant.” We appreciate Chat’s hard work and dedication to serve the MS community and are honored to have him as a member of the iConquerMS team. Would you like to accelerate MS research through iConquerMS, too? Here are some fun ways to join in!

If you are not already a member of iConquerMS, please consider joining!

Help keep MS research focused on the needs and priorities of people living with MS. Participate in the Our Questions Have Power program.

Share your experience with COVID-19 vaccines through COVER-MS.

Participate in other surveys and focus groups. Filling out your REAL MS surveys is the best way to be informed of these opportunities!

Have special skills like community building, outreach, graphic design or writing? Volunteer your talents to advance iConquerMS’s work!

June 2022 iConquerMS Spotlight

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.”

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

June 2022 Research Spotlight

RESEARCH OPPORTUNITIES

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

MSOCstudy
Multiple Sclerosis Online Course

Would you like to contribute to MS research?
Do you seek new knowledge about MS and lifestyle?
Sign up now!

Developed at the University of Melbourne, this online educational course aims to improve the health and wellbeing of people with MS.

What is involved for you?

- Completing an online survey before the course.
- Undertaking a free 6-week online course in your own time, taking 1-2 hours each week.
- Completing follow-up online surveys after course completion.

To sign up contact us now!

neu-research@unimelb.edu.au msonlinecourse.com.au

CSUDH
OCCUPATIONAL
THERAPY

Are you a mother with Multiple Sclerosis?
If so, we would love your participation!!

Why: We are Occupational Therapy students who are conducting a research study to better understand the different components of parenting among mothers with Multiple Sclerosis

What: 30-minute survey

Who: Mothers with Multiple Sclerosis age 18 years or older, with child(ren) 40 years or younger

For more information about this study, please reach out!

Secure Email: csudh.otmothering@protonmail.com iConquer MS™ 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.