

# May 2023 Newsletter



## How to Make Your Home More MS-Friendly

If you're a member of [iConquerMS](#), you know that we ask you questions about your ability to function at home and your satisfaction with daily activities. MS can cause problems with mobility and vision, which often makes everyday living a challenge. Making the right adaptations at home can make it easier to navigate and reduce the risk of falls. Read on for some ideas that can vastly improve your quality of life, allow you to regain some independence and, hopefully, make life a little easier.



**Declutter** – Too many items on countertops, desks, and tables make it harder to find things.



**Get rid of tripping hazards** – Keep the floor clear of anything that could make you stumble. Secure electrical and computer cords out of the way. Do the same with cords for curtains and shades.



**What's underfoot?** – Install thinner carpeting, hardwood or another smooth flooring so it's easier to move around. Remove throw rugs. If a space needs a rug or mat, secure it to the floor.



**Grab on!** – Handrails and grab bars are great safety measures, especially in the bathroom. Keep doors wide open or shut so you don't grab onto one that may move.



**Rearrange furniture** – Place your furniture strategically so you can lean on it to help you move around. Space it so there is ample room to easily maneuver a walker or wheelchair.



**Stairs made easier** – Have a sturdy banister on each side to hold on to. [Wheelchair ramps](#) are another option. An [electric chair lift](#) can help if there isn't space for a ramp.

### For the bedroom...

An [adjustable base bed](#) can make it easier to get in and out of bed. A bedside commode may be helpful to avoid having to walk to the bathroom in the middle of the night. Adjust the heat or air-conditioning with the push of a button with an [environmental control unit](#) (ECU). You can also use it to turn on the lights and open and close drapes. [Button hooks and zipper pulls](#) or a long-handled shoehorn can make getting dressed easier.



**Replace light switches** – Rocker-style light switches don't require as much hand strength to turn them on and off. Touch lamps, motion- or voice-activated lights and timers may also be helpful.



**Get in the zone** – Put the things you use often within easy reach. Use storage carts, hooks, hanging baskets or pegboards to keep things organized and handy.



**Set up work centers** – Create spaces where you can sit to do activities. Stock them with everything you need for that task.

## For a safer, more efficient kitchen...

Rearrange your cabinets so that the things you use most frequently are at eye level. If you have heavy dishes or baking sheets, stand them on end instead of stacking them. Keep heavy pots and pans on the counter instead of in a cabinet. That way you can slide them into place rather than lift. Use loop pulls on drawers and cabinets. Take advantage of stools or chairs that are high enough to let you sit at your countertop while you cook or use the sink. Gather everything you need to prepare a meal ahead of time and use a cart to roll your supplies where you want them.

A number of kitchen aids make preparing meals easier and safer, such as a [grabber](#) to help you reach items on high shelves, an electric can opener, jar openers, utensils with easy-grip handles, a food processor or rocker knives to help cut food with less effort. Get nonskid mats for counters so your bowls and cutting board won't slide around.



If you're in a wheelchair, lowering a countertop makes it more accessible. Removing cabinets from below the sink permits a wheelchair to slide underneath. Moving the faucet to the side of the sink makes it easier to reach and use.



**We can handle this!** – Switch out round knobs for lever-style handles. Placing rubber grips over existing doorknobs can also help. These same strategies can be used for water faucet handles, too.



**Widen doorways** - Simpler options include removing the door entirely, installing pocket doors that slide inside the walls, or reversing doors to provide more space in a small room.

### High Contrast Colors



**Use contrasting colors** – Dark and light colors when paired together make things easy to see. Mark the edges of steps and door frames with paint or tape to make them more visible.



**Minimize Glare and Low Light** – Install blinds or sheer curtains to block out incoming sunlight that causes glare. Replace fluorescent bulbs with incandescent ones. Use night lights to illuminate walking paths at night.



**Rely on Velcro** – Use it to fasten clothing, keep seat cushions from sliding, hang a cane on the wall, or secure the remote so it doesn't get lost.



**Rise up** - Raising the furniture can make it much easier to get up. Lift chairs are a popular option. [Furniture risers](#) can be used for chairs and other furniture, too.

### For the bathroom...

Install a raised toilet seat to make getting up and down from the toilet easier. Use a tub bench or shower chair so you can sit while you wash and a handheld shower head that reaches down to you. For extra fall prevention, put a nonskid mat inside the tub.

Put everyday hygiene supplies in a basket on a low, easily-accessible shelf. Choose pumps and squeeze bottles instead of bottles with screw tops. Use combs and toothbrushes with easy-grip handles. A long-handled sponge can make it easier to reach less accessible areas of your body. Roll up towels and store them next to the tub for easy access.



For those in a wheelchair, wall-mounted sinks are more accessible because they have extra space below. Removing cabinet doors also makes the sink and items below it easier to reach.



**Go remote** – Remote controls allow you to manage all sorts of gadgets without walking from room to room. [Smart home systems](#) can connect all of your electronic devices to your smartphone or tablet.



**Keep relaxation in mind** – Stress can trigger or make MS symptoms worse. To relieve tension, try using scents you like, replace an uncomfortable sofa, or have humorous books or movies on hand.

If you're having trouble functioning at home, it's important to consult with your healthcare team before making any significant home modifications. An occupational therapist can address your needs, functional status, interests and goals to make your home as safe and accessible as possible. Many provide these services on an in-home basis. He or she will also help identify and address any potential hazards that may exist. The National MS Society website has a useful [tool](#) to help find these types of providers and other important resources for people with MS.



## **Welcome to the Team, Jordan!**

We are thrilled to introduce you to Jordan Caines, the newest member of the ACP team! Jordan joined ACP in March as the Program Manager of the iConquerMS [Research Inclusion Diversity and Equity \(RIDE\) Council](#), which is working to bridge the gap between awareness and full representation of racial, ethnic, and gender minority groups in research. Jordan brings with him a background in community development and crisis management, having most recently served as Assistant Director of Education and Outreach for [Lines for Life](#), a non-profit dedicated to preventing substance abuse and suicide, and promoting mental wellness. His experience and perspective will be valuable assets to the RIDE Council as they bring together diverse stakeholders within the MS community to discuss and strategize on how to best build



genuine partnerships that encourage minority participation both within the iConquerMS network and beyond.



Jordan was born and raised in Culver City, CA and currently lives in Koreatown, one of the most diverse neighborhoods in Los Angeles. He and his wife, Elisabeth, are newlyweds, recently married in December. Jordan did his undergraduate studies at the University of Oregon, earning a Bachelor's degree in Sociology and Ethnic Studies. After graduation, he worked for a few months as a counselor at a treatment facility for adults with mental health issues. At the beginning of COVID, Jordan was fortunate to find a temporary position as an emotional support outreach specialist and community liaison for Lines for Life. In that role, he connected individuals in need to local and statewide mental health resources. He states, "I still got to chat with, communicate and help people, but was able to do it virtually."

Jordan transitioned to a permanent position as Assistant Director of Education and Outreach on Lines for Life's Youth Line (a peer-to-peer youth crisis line).



The bulk of Jordan's role was overseeing the School Suicide Prevention Wellness team. In Jordan's words, "It was a four-person team that communicated with every school district across the state of Oregon to make sure they had adequate mental health support in their school. I also oversaw the outreach team, so I would go into schools, mostly in and around the Portland metro area, giving presentations to middle and high school students on ways to support themselves when they were experiencing mental health challenges. We tried to give them a space to talk about whatever they wanted to talk about. Students were pretty overwhelmed, especially with COVID and so much going on in the world. That was an awesome experience."



When not at work, Jordan and Elisabeth enjoy going on hikes and exploring national parks. They also love to travel and tour new places. Jordan shares, "We were in Hawaii for Thanksgiving this past year. We spent almost a full week there and that was a lot of fun. It was beautiful." Sports are also a big part of his life. According to Jordan, "I'm a diehard Yankees fan. I watch every game with my wife... I played a bunch of sports growing up. I love baseball and played it all through high school. I wore the number two in every single sport for Derek

Jeter, one of the greatest athletes of all time. Growing up my dad was my baseball coach, too. It was an amazing way to bond with him and spend time with him.”

Jordan has a strong passion for uplifting and highlighting voices that may have been historically underserved or not represented to the fullest extent. When asked where this passion came from, he states, “I grew up in LA, which is an extremely diverse area. My high school class when I graduated was the second most diverse high school class in the United States. Going to Oregon was definitely a bit of a culture shock for me at first. It was a



*Jordan and his family*

predominantly white setting. I went from not really thinking about my identity and how I looked to being the only student of color in a class of thirty people. At first it was a little bit daunting and it was hard for me to build community and make friends there. Pretty early on I regretted my decision to go far from home and struggled with feelings of not fitting in... I used that as an opportunity to grow, branch out and experience new things. As soon as I found ethnic studies, I met some of the most amazing people I’ve ever met and had some of the most wonderful, insightful professors. I dove deep in my studies and learned a lot about historical inequalities that were surprising to learn about. It shaped much of what I want to pursue in the future, which is dismantling systems of inequality wherever I can, whether that’s in my personal life, or in professional relationships.”

***“With ACP, the mission is crystal clear. Find a cure for MS. I love this organization’s ability to have such an amazing collaborative approach.”***

Jordan was drawn to the position at ACP for a number of reasons. In his words, “Honestly, the first thing that stuck out to me is that ACP is based in Waltham, which is where my aunt lives right now. That was an interesting connection, but when I dove deep and read about all of the amazing programs that ACP offers, I was immediately blown away by their mission and how ACP is so willing to collaborate

with other organizations that are either researching MS or doing anything that involves MS. Sometimes nonprofits get caught up in their own work. At least in my experience, sometimes they forget about their mission and the reason why they are an organization... I’ve only been here a short time, but it seems like everyone on the ACP team is so willing

to do whatever they can, to be as flexible as possible and to be a team player and work with others, to surround themselves and focus on the goal. I just really love that.”



When asked what gifts and skills he thinks he brings to the ACP team, Jordan shares, “Some positive feedback I’ve received in the past is that I make people feel heard. From a very early age, my father instilled in me how to develop good active listening skills. Now, I try to focus on and understand what people are saying, swap perspectives and hear where they are coming from. I feel like I do a really good job at processing information and communicating it to other people... When I’m passionate about something, whether that’s a job, an organization or sports, I’m good at getting other people excited, too. What I really want to bring to the table with ACP, especially with the RIDE council, is elevating people’s voices. I’m really excited to meet everyone on the team and see what they want to do and what they want to elevate and do all that I can to make them feel heard.”

When asked about his vision for the RIDE council, Jordan states, “A lot is dependent on what members of the RIDE Council want it to be. I’d like to elevate the projects they want to do, whether that’s through social media or other media campaigns... The fact that there are three sub-councils (Black/African American, Latino/Latin X and Emerging Voices for those from other underserved or underrepresented groups) shows that every group of people has their own experience and set of challenges or barriers that come with their identity. I think each one of the sub-councils brings to the table a unique perspective that I’m really excited to learn more about and help them vocalize.”

We are excited to have Jordan on board, lending his experience and insight to the RIDE Council. Their work to diversify MS research will bring us one step closer to ensuring that its findings apply to and benefit people of all racial backgrounds, allowing all individuals living with MS to receive the best care possible. The prospects for 2023 are looking bright! Stay tuned!





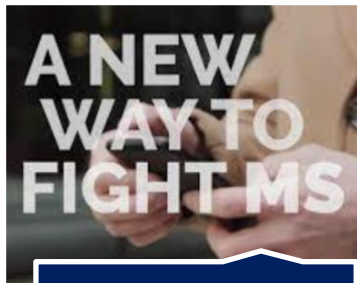
## May 2023 Donor's Corner

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.**



ACP Repository



iConquerMS




Inclusive Engagement  
in MS Research

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.


This month, we're highlighting how your generosity enables ACP to provide valuable information about living with MS to network members and the greater MS community.

ACP's [Research, Inclusion, Diversity, and Equity Council](#) (RIDE Council) has developed resources to address some of the most common challenges that people with MS face. Click on any of the images below to access the full resource:

 **iConquerMS™**


**HEALTHCARE  
SELF-ADVOCACY TIPS**  
FOR PEOPLE LIVING WITH MS

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

 **iConquerMS™**

**FINDING PEER SUPPORT**  
FOR PEOPLE LIVING WITH MS

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

 **iConquerMS™**


**BUILDING A  
HEALTHCARE TEAM**  
TO HELP MANAGE YOUR MS

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

 **iConquerMS™**

**FINANCIAL ASSISTANCE  
FOR MS MEDICATION**

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

 **iConquerMS™**

**FINANCIAL PLANNING RESOURCES**  
FOR PEOPLE LIVING WITH MS

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

[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.



## May 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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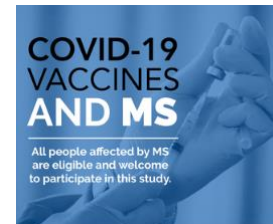
Our Questions Have Power

## iConquerMS Spotlight

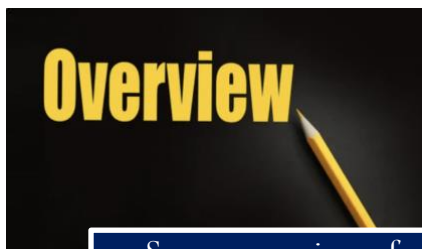
### COVER-MS Update

#### How effective are COVID-19 vaccines in people with MS?

[iConquerMS](#) is gathering important information about COVID-19 vaccines and how they work in people affected by MS. The [COVER-MS study](#) currently has over 1,600 participants. This [real-time data display](#) summarizes the information they have provided to date. Overall, [results](#) show the frequency of vaccination reactions in people with MS is similar to that reported in the COVID-19 vaccine clinical trials.



Want to learn more about what we've learned from COVER-MS so far?



See an overview of COVER-MS results



Watch Chat with Chat, Episode 4

**BUT WAIT  
THERE'S  
MORE!!**

Through a partnership with Quest Diagnostics and the National MS Society, we've recently launched a COVER-MS [sub-study](#) looking at the effectiveness of COVID-19 vaccines at preventing the virus in people with MS. 300 COVER-MS participants will donate blood every 6 months for the next 2 years. These samples will be analyzed to determine how MS drugs and other factors affect the immune response (antibody levels) to COVID-19. We are currently inviting participants to return for a second blood draw and have been able to provide them with antibody results from round one. Analysis of these data is underway, stay tuned for the results!

COVER-MS is open to anyone who has received a COVID-19 vaccine or plans to receive one. To join the study, [log in](#) to your iConquerMS account. Not already a member of iConquerMS? Please consider [joining](#) today! Thanks for your help in conquering COVID-19!



# RESEARCH OPPORTUNITIES



**Your health data  
has power!**

## Opportunity to provide input to the National MS Society

We're working with the National MS Society to help provide input to their strategic planning process through a series of focus groups. They would like to hear from people who **live in the US** and have been **diagnosed with MS** or are **parents, adult children, and spouses/partners of people with MS**. Family members are welcome!

The meetings will be 2 hours long, conducted via Zoom, during the months of June, July and August. Those who are selected to participate in one of the focus group meetings will be paid \$200 for their involvement.

If you are selected as a participant, any personal or health-related information you disclose will remain confidential. Your perspective and experiences will be recorded and shared with the Society, but will not be connected with your name or other identifying information. All participants will receive a report with the key findings from these discussions.

If you're interested in participating, please [click here](#) to provide some information and indicate your availability. If you have any questions, please email us at [info@iConquerMS.org](mailto:info@iConquerMS.org).

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# 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




For more information, contact Edson Flores

(833) 727-1887

enrl@uic.edu

Keyword: TEAAMS

<https://projectteams.ahs.uic.edu>





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

### 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)

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.

### 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?

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.

### 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](mailto:MSDietStudy@healthcare.uiowa.edu)

→ [wahls.lab.uiowa.edu/join-study](http://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!





**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.