

September 2023 Newsletter



Meet Rob, an advocate for inclusion

It's our pleasure to introduce you to Rob Sarles, a member of the iConquerMS [Research Inclusion Diversity and Equity \(RIDE\) Council](#)! The RIDE Council is working to bridge the gap between awareness and full representation of racial, ethnic, and gender minority groups in research. Rob holds a deep-seated passion for this effort, which will bring us one step closer to ensuring that all individuals living with MS can receive the best information, outcomes, and care possible.



Rob is originally from southeast TX and currently lives about an hour north of Nashville, TN. He is married and has 2 children. Rob is a musician, through and through. He studied music in college, earning a Bachelor's degree in music and a Master's in music theory and composition.



“Music is my main thing. I’ve directed choirs and performed. Voice is my primary, but I also play piano and trumpet. I’m pretty limited in terms of what I can do musically now, but I have a little studio where I can do limited things. I can still enjoy it, listen to it and go to concerts.”



Rob in his music studio

Rob was diagnosed with MS 10 years ago. He has been disabled for about 5 years. He shares, “At this point I’m still relapsing remitting, but possibly secondary progressive MS. They haven’t given an official upgrade yet. I started experiencing my first symptoms in 2008. My hands and feet went numb for a few weeks. My doctor did all of the MS diagnostics except for a lumbar puncture and didn’t find anything. About 5 years later I

was walking home from work and realized that I didn’t know if I could take another step. I went to my doctor the next day and he immediately ordered an MRI. They found some lesions on my spine and admitted me to the hospital. I spent several days there. They didn’t give me an official diagnosis when I left the hospital, they waited until my first neurologist appointment to break the news to me... I’ve been on [Kesimpta](#) for a little over 2 years now and it seems to be helping some. There are no new lesions. I’ve still had some disability progression, but at least as far as the MRIs go, it’s been clean.”



Rob “celebrated” the 10-year anniversary of his MS diagnosis by creating his Instagram, [#thatissoMS](#). In his words, “I share stories about my experiences with MS, my experiences with the RIDE council, and things that I’ve learned in research news. I’m excited about it, doing my tiny little part. It helps to get the word out about the RIDE Council and everything we’ve been doing. It’s also a creative outlet.”



How did you first hear about ACP? “I signed up for iConquerMS in 2018, about 5.5 years ago.”



What about ACP’s mission inspires you the most? “I really like the cooperation between the patient and research. That it’s intertwined. It’s all about communication. I think that really will accelerate research and progress toward a cure.”



Why do you serve on the RIDE Council? “Racial equity, inclusiveness and diversity have been really important to me since I was a child. I’ve always valued them and fought for them. I wanted a chance to be a part of something like that.”

To ensure its results apply to all, medical research should include everyone, regardless of race, ethnicity, orientation, or economic status. The RIDE Council discusses historical underrepresentation in research and ways to increase meaningful participation. In Rob’s words, “A big launching point for the RIDE Council was defining the obstacles that might keep people who are underrepresented from being a part of research. Then we crafted that message into [flyers](#) where we can start to amplify that and try to get more people involved... We’ve been distributing flyers in doctor’s offices. So far, the reception has been good. We’ve been talking about setting up tables at different events, like health fairs. I’m hoping to be a part of a local music festival that they have near me. It has music and food, but organizations also set up booths there. I’m hoping to be able to have a booth there to give out more information about the RIDE Council and ACP.”

What gifts and skills do you bring to the RIDE Council? “I’m a very curious person. I’m constantly trying to learn. I am creative. I like to think outside the box. I’m empathetic not just to my own personal needs and causes, but also to other people. And I’m not afraid to stand up for the needs of other people as well.”



“I love to see that RIDE Council values are growing into concrete opportunities for research. They are being built into new projects. I love to see our influence grow. It’s not just an idea or a value, it’s a movement that researchers take seriously. This isn’t just theory this is what’s happening. This is what patients want and need.”



What is your favorite part of serving on the RIDE Council? “There are so many interesting people. It’s really cool to hear other people’s experiences and stories in the breakout sessions that we have. Things I haven’t thought about before. I learn so much from them and that makes me a better person.”



What is the RIDE Council’s biggest challenge? “The first thing is getting the word out. It’s a grass roots movement and so it takes time to get the snowball rolling. I also think history is a challenge. Inequities in research that have happened in the past have placed stigmas on research. Also, I think researchers often take the path of least resistance when it comes to filling slots in their studies. There are people that want to be involved in research, but they live in rural areas or they don’t have access to transportation and those people end up being underrepresented because the researchers overlook them. You have to make a conscious decision to create diversity and inclusivity. It doesn’t happen by accident.



How can the RIDE Council overcome these challenges? “I’ve thought a lot about that and I would love to see a network of alliances built between pharmaceutical companies, educational institutions and doctors. Something that links all these people together. I could see an organization like ACP being the hub that that opens up communication rather than each group reinventing the wheel on their own. I’ve never had a doctor or anyone say, “Would you like to be part of a study?” or “Are you interested in being a part of research?” or anything like that. If doctors were taught in medical school or if the communication started in their training to put this network in place, I think it would transform research where everyone was working together.”



Embracing diversity in MS research benefits the entire MS population. The RIDE Council advocates for inclusive research, which could lead to improved healthcare and quality of life for all those affected by MS. Want to be a part of this exciting movement? [Join](#) iConquerMS to find out how you can contribute to making MS research more inclusive!

iConquerMS™

COME JOIN OUR NETWORK!

iConquerMS is a research network committed to prioritizing patient voices and needs. It is supported by the Accelerated Cure Project, a patient-founded non-profit organization dedicated to accelerating MS research.

For information on how to join, send us an email or visit us online!

1 - 844 - 897 - 1211
info@iConquerMS.org
www.iConquerMS.org



Rob “walking” his daughter down the aisle at her wedding last November

Rob shares about his identity as a disabled person... “Even though I am quite limited in what I am able to do, I still want to do what little I can to make a difference. Whether it’s advocating for people with MS who are underrepresented or discriminated against, or participating in research personally (but, unfortunately, people at my disability level often don’t qualify for studies). This also applies to finding ways of doing the things I enjoy like music or travel, even though I have had to make a lot of adjustments.”



Rob dressed in his steampunk Halloween costume

3. Turmeric

Turmeric is a bright yellow, fragrant spice that is commonly used in Indian cooking. Its main ingredient, curcumin, has been shown to have a number of benefits.



According to a [2017 study](#), curcumin can potentially reduce the severity of immune system-related diseases like MS by affecting different cells that are involved in the immune response.

[Researchers](#) in Pakistan demonstrated the potent anti-inflammatory and antioxidant properties of curcumin, and its therapeutic potential against MS.

4. Ginger

Ginger is a rhizome with a potent, spicy flavor. It contains a number of different anti-inflammatory compounds, including gingerols and shogaols.



There is [evidence](#) that 10-gingerol is important in reducing inflammation in the brain and spinal cord.

According to a [2022 review](#), gingerols and shogaols may reduce the levels of inflammation and oxidative stress in neurodegenerative diseases like MS.

5. Avocado

Avocados are a great source of healthy monounsaturated fat. They are also rich in antioxidants, which help to fight inflammation.



[Researchers](#) at UCLA showed that eating avocados dampens the body's inflammatory response.

A [2019 review](#) found that a combination of avocado and soybean oils may have a beneficial effect on inflammatory diseases.

Can MS cause digestive problems?

[Research](#) shows nearly two thirds of people with MS experience at least one persistent GI symptom. Results show that the four most common symptoms are constipation (37%), indigestion (30%), difficulty swallowing (21%) and fecal incontinence (15%).



6. Flaxseed

Flaxseeds are another rich source of omega-3 fatty acids. They also contain [lignans](#), which are known for their anti-inflammatory effects.



A [2019 review](#) suggests flaxseed may have anti-inflammatory effects in the body, though the authors note that further study should be done to clarify this link.

Australian [researchers](#) found that flaxseed oil supplementation in people with MS is associated with a 60% lower relapse rate. They also state that more research is needed to confirm these results.

7. Walnuts

Walnuts are also a good source of omega-3 fatty acids. They're packed with antioxidants, fiber and magnesium, all of which have important roles in regulating inflammation.



According to a [recent review](#), eating walnuts not only reduces some signs of inflammation but also has other health benefits like lowering triglyceride and cholesterol levels.

[Investigators](#) in Iran found that walnut oil significantly reduced disease severity and inhibited plaque formation in a mouse model of MS.

Want to read more about MS Diets?

Our [August 2019 newsletter](#) covers several dietary strategies for people with MS, including the scientific evidence to support, or refute them.



8. Olive Oil

There's [evidence](#) that components of extra-virgin olive oil known as phenols may help prevent the inflammatory processes involved in a variety of diseases like MS.



Spanish [researchers](#) suggest that extra-virgin olive oil may protect nerve cells against damage and degeneration in a mouse model of MS.

Olive oil is an important part of the Mediterranean diet. According to a [2022 study](#), this way of eating is linked to less disability in MS.

There is no agreement or guidelines to follow when it comes to what people with MS should eat. However, there is evidence that some foods and nutrients might help with MS symptoms. It is important to talk to a doctor or nutritionist before making significant changes to your diet. One concern is that specific diets could be too strict, making you miss important nutrients and causing problems. Emphasizing a particular food can have the same effect. More research is needed to know the benefits and risks of diets for MS. These studies are happening now, which is exciting because diet is something people can control to some extent, giving them more power over the disease. ACP's main goal is to support research into topics like this, which could improve the lives of people with MS over time.

An advertisement featuring a man in a pink shirt looking at a tablet. The text reads: "PARTICIPATING IN MS RESEARCH has never been easier for people living with MS!". At the bottom, it says "iConquerMS" and "LEARN MORE: iConquerMS.org".

**PARTICIPATING IN
MS RESEARCH**
has never been easier for
people living with MS!

iConquerMS™ LEARN MORE:
iConquerMS.org

September 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

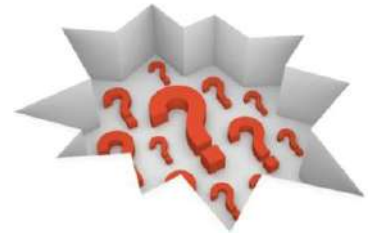


iConquerMS



Inclusive Engagement
in MS Research

Despite progress in understanding MS in minority populations, substantial gaps in our knowledge remain. Filling these gaps is limited by a [lack of diversity](#), or low enrollment of minority populations, in MS clinical trials.



This month, we're highlighting how your generosity enables ACP to spread the word about the work that the iConquerMS [Research, Inclusion, Diversity, and Equity Council](#) (RIDE Council) is doing.



The RIDE Council is focused on broadening participation in research by highlighting the voices and experiences of people from traditionally underrepresented communities. Their work brings us one step closer to ensuring that all individuals living with MS can receive the best information, outcomes, and care possible.

The RIDE Council provides key support to all stakeholders in MS research:

		
<p>People with MS have a group exclusively focused on ensuring their community is represented in clinical trials.</p>	<p>Researchers have a resource to help ensure they meet diversity goals and requirements in their studies.</p>	<p>Organizations have a resource to help reach and meaningfully include historically marginalized groups in their work.</p>

[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.



September 2023 iConquerMS Spotlight

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. Hosted by our research collaborator, Chat Ngorsuraches, these conversations cover a wide range of interesting topics, including [complementary and alternative medicine](#) (CAM).



A variety of medications are used to treat MS. At times, individuals living with the disease may explore CAM as a way to relieve unpleasant symptoms and enhance their quality of life. This is commonly done alongside their prescribed treatments for MS.

Most alternative treatments have undergone very little (if any) scientific study to evaluate their safety and effectiveness. When exploring CAM therapies for MS, it's essential to find reliable information. In [episode 8](#) of the Chat with Chat webinar series, Dr. Sarah Minden from Brigham and Women's Hospital sheds light on CAM therapies and suggests trustworthy sources for them.

Use of Complimentary & Alt
Medicine (CAM) by Members of
iConquerMS

Sarah Minden, MD

Accelerated
Cure
project

iConquerMS™
ACP Repository™

MS Minority
Research
Engagement
PARTNERSHIP NETWORK

Talk with your doctor before starting any new therapy. It's important to keep him or her informed about what you take (or what is done) and any changes you experience.

Ten episodes of Chat with Chat have aired to date. In case you missed, or would like to revisit any of them, they can be found [here](#). A heartfelt thank you to Chat and his colleagues for making this educational resource possible.

iConquerMS brings together people with MS, their care partners, researchers and others to understand MS and search for solutions. If you haven't already, please consider [joining](#) today!

iConquerMS™

Why Should I Participate in iConquerMS?

By participating, you can **help influence MS research** to align with what matters the most to **you & the MS community**.

You'll be helping to **provide researchers with valuable insights** that can help them identify patterns and trends that may lead to **new MS discoveries**.

September 2023 Research Spotlight

RESEARCH OPPORTUNITIES

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



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](#) 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!

STUDY2022-0084-MOD006
Effective: 8/11/2023
UIC Office for the Protection of Research Subjects

Research Opportunity

**Researchers at the University of Illinois Chicago (UIC)
Invite You to Participate in a Voluntary Research Study**

This is a nationwide, remote study that is examining the effects of two Internet-delivered programs for improving cognitive health among people with MS.

All participants in this study will complete online questionnaires, virtual cognitive and mobility testing, and wear an accelerometer. An accelerometer is a small device that measures physical activity by measuring steps/day.

The entire study can be conducted at home as no in-person visits are needed. Also, currently physically inactive refers to those who are not doing enough physical activity.

Participation in the study will last 12 months and participants will receive \$50 in compensation via gift cards for completing the 3 measures for a total of \$150.

Initial eligibility

- **Diagnosis of multiple sclerosis (MS)**
- **18 years of age or older**
- **Internet and email access**
- **Currently physically inactive**
- **Able to walk without assistance**

**For More Information:
Contact the Project Coordinator**

Key Words: BIPAMS-Cognition

Phone: (833) 329-1441

Email: bipamscognition@uic.edu

Website:

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



RESEARCH OPPORTUNITY

University of Illinois at Chicago



Exercise Training for Managing Major Depressive Disorder in Multiple Sclerosis

METS for MS

The **Mood and Exercise Training Study for Multiple Sclerosis (METS for MS)** is looking at the use of exercise as a non-medicinal treatment for persons with MS who also have depression. METS for MS involves the remote delivery of a 4-month exercise training program with a 4-month follow-up period.

The study involves 3 University of Illinois Chicago site visits over the course of 8 months. Site visit testing includes mental health screeners, muscle strength testing, aerobic testing, walking speed testing, and cognition testing.

Coaching and all equipment needed for exercises will be provided by the study. Participants will be paid \$100 for each site visit completed.

Eligibility:

- Multiple sclerosis diagnosis
- Major depressive disorder
- Internet and e-mail access
- Willingness to complete training
- Physically inactive
- Able to walk
- 18-64 years of age
- English as a primary language
- Live within 100 miles of Chicago

Benefits of Participating:

- Improve your health and wellness through exercise training
- Contribute to ongoing research on persons with MS



FOR MORE INFORMATION
CONTACT THE EXERCISE NEUROSCIENCE RESEARCH LAB:
1(833)413-0280
METSFORMS@UIC.EDU



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

Contact us for more information

(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?

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

→ wahls.lab.uiowa.edu/join-study



Changing Medicine.
Changing Lives.®



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.