



Dear National MS Society Connection Program Volunteers,

The participation of people living with MS in research is pivotal to research success to stop disease progression, restore function, and end MS forever.

Opportunities include:

- responding to surveys or other observational studies
- providing input and feedback about topics for research and contributing to the design of study protocols
- participating in clinical trials, which are necessary to develop safe and effective solutions for people affected by MS
- donating DNA for genetic studies
- arranging for tissue donation; blood samples also can be donated
- sharing information with others

**You can advance MS research by sharing your voice**

The research community values your thoughts, ideas and questions about where research is headed, or should go. “MS research is not just about biology — it’s about everyone contributing their questions, ideas, solutions and time,” says Society Chief Advocacy, Services and Research Officer, Tim Coetzee, PhD. Today, people living with MS are driving and changing research in many ways.

Please use the suggested discussion questions (on back) to generate conversation in your group about research and how you can help advance it. Or, distribute the resource sheets (last page) to your group members.

The Society reviews studies carefully to ensure that they are appropriate for people with MS. If you are approached directly by a researcher (from academia or industry) about an opportunity to participate, please get your staff partner’s approval before sharing the opportunity with your group.

We hope that your group has the information they need to help advance MS research. Thank you for connecting this information to your community.

Sincerely,  
Monica Aden,  
Manager of Program Development, Connection Programs  
Services Department

## **YOU CAN ADVANCE MS RESEARCH**

### **SUGGESTED GROUP DISCUSSION QUESTIONS**

- Why is it important to participate in research?
- What does participation in research mean to you?
- What are your thoughts on the wide variety of ways that people can advance MS research?
- What are the risks of participating in research?  
Do you know how to protect yourself?
- If you cannot or prefer not to participate in a clinical trial, how will you share your voice to advance MS research?
- How comfortable do you feel getting involved in surveys or initiatives like iConquerMS™ and NARCOMS?
- How will you share information on advancing MS research with others you know who are affected by MS?
- If you have participated in research, what was your experience?
- How likely are you to participate in MS research?
- What concerns do you have about participating in MS research?



## RESOURCES TO LEARN MORE ABOUT HOW YOU CAN ADVANCE MS RESEARCH

At [nationalmssociety.org/research/participate](https://www.nationalmssociety.org/research/participate), opportunities include clinical trials, donating DNA for genetic studies, responding to surveys or other studies, arranging for tissue donation (blood samples also can be donated). Assess each opportunity and make an informed decision before agreeing to participate — understand the possible benefits and risks. Read more in “Participating in Clinical Trials: A Guide for People with MS” at:

<https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Research/Clinical%20Trials/ClinicalTrialsGuide2014.pdf>

Request a print copy of this guide at 1-800-344-4867 (option 1).

The research community values your thoughts, ideas and questions about where research is headed, or should go. Today, people living with MS are driving and changing research in many ways through the Society and other organizations. We are moving MS research forward, faster.

**iConquerMS™** is a patient-powered research network that empowers people living with MS to shape and participate in research online by completing surveys about daily experiences and symptoms, sharing medical records, suggesting research topics and questions, and contributing to the design of research studies. Privacy and identify are safeguarded at the iConquerMS portal and all contributed information is de-identified before being shared with the scientific community. Responses are pooled with information from thousands of other people, and then used by researchers to detect patterns that would not be visible otherwise — to build insights into the causes of MS, who will respond best to various treatments, and new, improved treatments. Interested in driving, shaping and accelerating MS research into topics that matter most to you? Join at [iConquerMS.org/join](https://www.iConquerMS.org/join).

**NARCOMS** (North American Research Committee on Multiple Sclerosis) is an ongoing patient self-report registry that captures the real-life experiences of people living with MS. NARCOMS strives to improve clinical care and quality of life for persons with MS and their families, through increased knowledge about MS. For over 20 years, NARCOMS participants have provided valuable information about themselves and their disease course through confidential questionnaires. This information fuels research that provides a deeper understanding of MS and how it affects the lives of people living with MS, and may lead to more effective MS treatments and care. Participate in NARCOMS at [NARCOMS.org](https://www.NARCOMS.org), by mail, or call 800-253-7884 (weekdays 8 a.m.-5 p.m. CT). All information provided is kept confidential.