



National
Multiple Sclerosis
Society



Group Leadership Call: May 20, 2021 3PM and 7PM EST



Hosted By:
Brittany Herrmann
Manager, Community Engagement
Nashville, TN

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YEARS OF **PROGRESS**

Group Leadership Call: May 20, 2021 3PM and 7PM EST



Hosted By:
Mollie Burns
Manager, Community Engagement
Philadelphia, PA

Diversity, Equity & Inclusion Statement

The National Multiple Sclerosis Society is a movement by and for all people affected by MS.

Our voices and actions reflect diversity, equity, and inclusion.

We welcome and value diverse perspectives.

We actively seek out and embrace differences.

We want everyone to feel respected and be empowered to bring their whole selves to ensure we make the best decisions to achieve our mission.

Today's Call

- Presentation on Summer and MS: Heat Sensitivity, Cooling, and Vitamin D
- Society Resources for Connections Volunteers
- Questions, Feedback, and Discussion

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Summer is Hot Hot Hot

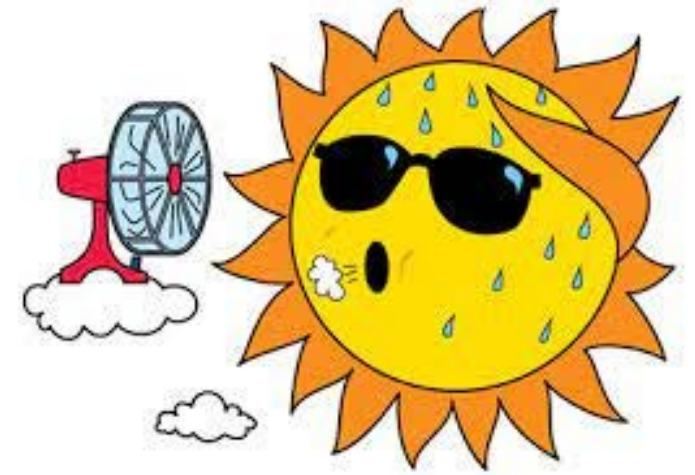
Heat Sensitivity, Cooling, and Vitamin D

Heat Sensitivity

- Changes in temperature can worsen MS Symptoms by impairing the ability of demyelinated nerves to conduct impulses
- Symptoms commonly affected are fatigue, sleep disturbances, stiffness/spasticity, Uthoff's sign (vision)
- Temporary worsening of symptoms

Vitamin D

- Bodies need 15 minutes of sun a day
- Can obtain small amounts from food
 - Oily Fish (salmon or tuna)
 - Beef Liver
 - Egg Yolks
 - Pork
 - Fortified Milk or juices
- Supplemental Vitamins can be easiest





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Together We Are Stronger.

Tips for Staying Cool

- Staying inside during hottest times of day
 - Exercise during morning or evening cooler hours (or inside)
- Cool showers or bathes to lower temperature
- Drinking cool beverages and staying hydrated
 - Avoid diuretics like alcohol and caffeine
 - Keep in mind bladder issues
- Wear breathable clothing
- Track Heat Index
 - Humidity plays a large role in heat sensitivity
- Fun with ice!
 - Ice cube on pressure points
 - Fan with a bowl of ice in front of it



Types of Cooling Products

- Air Conditioners/HVAC
- Personal cooling systems
- Cooling Garments
 - Scarfs, hats, bracelets/anklets, blankets
 - Cools by targeting pressure points
- Cooling Vest
 - Targets core temperature



Types of Cooling Vests

- Ice Gel Packs
 - Freeze within hours and lasts for 3-4 hours
 - Moderate Weight/Temp – adjust based on number of packs
 - Effective in all climates and worn beneath clothing
- Phase Packs
 - Activated in Ice Water – Do not need access to freezer
 - Lasts for 2-3 hours
 - Adjustable weight and temperature
 - Effective in all climates and worn beneath clothing



Types of Cooling Vests

- Evaporative Cooling
 - Soak garment in water, as it evaporates it cools
 - Effective in low humidity climates
 - Lightweight and worn over clothing – exposed to air
- Hybrid Cooling Technology
 - Water absorbing crystals – Soaks in water and evaporates
 - Once soaked you can also freeze the garment for longer effects
 - Effective in all climates and can wear beneath clothes (will be damp)



MS Navigator Assistance

- Available to discuss grants and resources to assist in obtaining cooling products
- NMSS has collaborative relationships with many cooling product vendors to streamline purchasing a product
- Connect via WebChat, Email, or over the phone
- ContactUsNMSS@nmss.org
- 800-344-4867 Monday-Friday 7am – 5pm MST

Resources

- US Department of Energy Weatherization Assistance
 - Increase Energy Efficiency of homes and reduce costs
- Air Conditioners and HVAC
 - Habitat for Humanity ReStores
 - StartGrants.com
 - MS Foundation
- Cooling Vests and Products
 - MS Association of America (Specific product packs to choose from)
 - MS Foundation (February 1st – June 1st)
- Cooling Centers
 - Temporary air-conditioned public spaces set up by local authorities
 - Call 2-1-1 for listings

Takeaways

- Diet/Nutrition plays a role in temperature management
- There are lots of products to help stay cool and resources to access products
- Staying cool can require creativity
- Reach out to MS Navigator for additional support

Questions?





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Society Resources

Connect with your Staff Partner

- E-mail us any time at peerconnections@nmss.org
- Look for outreach from your staff partner in the coming months to schedule a 1:1 check-in

Visit the Peer Connections Volunteer Website

www.nationalMSSociety.org/peerconnectionsvolunteers



For Peer Connections Volunteers

- Resources for Peer Connections Volunteers
- Call Archive
- Educational Resources & Toolkits

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IN THIS ARTICLE

- Peer Connections Volunteers
- Community Resources to Share
- Difficult Conversations & Crisis Support
- Recursos Para Voluntarios

Peer Connections Volunteers

Comprehensive resources for all Peer Connections Volunteers, including Society policies, volunteer support resources, and group leadership & meeting guides.

- Welcome to the National MS Society
- Active Listening
- Code of Conduct
- Difficult Conversations & Crisis Support
- Disability Language and Etiquette
- Diversity, Equity & Inclusion Statement
- Medical Advice & Medicine Sharing
- MSFriends Conversations Quick Guide
- MSFriends Establishing Boundaries
- Non-National MS Society Relationships FAQ
- Self-Help Group Disclaimer
- Solution Focused Conversations
- Tips for Hosting Virtual Online and In-person Groups
- Virtual Meeting Resources

Community Resources to Share

Learn more about community and nationwide resources that can be shared with individuals and group members.

- Veterans Resources
- Assistive Technology Resources
- Service Animal Resources
- Crisis Support Resources
- Emotional Support Resources
- Additional Society Support Resources
- Tips for Successful Telemedicine

Difficult Conversations & Crisis Support

Information, materials, and guides designed to address challenging situations and connect individuals with appropriate resources.

- Crisis Support Resources
- Emotional Support Resources
- Difficult Conversations & Crisis Situations
- Managing Derogatory, Discriminatory & Racist Statements



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Join the Peer Connections Volunteers Facebook Group

Connect. Support. Encourage. Relate.



[Click Here](#)

A place for National MS Society volunteers to interact with other Self-Help Group leaders, MS Friends, and Peer-to-Peer volunteers. This group provides access to valuable resources and offers a safe environment for collaboration and idea-sharing so you can best support your group members and fellow MS community.

**MS
WARRIOR**



*MS Warrior
Leader
Support Group*

*A Support Group for
MS Group Leaders*

*Join us on Zoom
3rd Thursday of the month @ 4pm (EST)*

*Meeting ID 84207053474
Passcode- Warrior*

*Contact Monica at
SPEAKMSTOME@GMAIL.COM*



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Group Meetings

In Person Meeting Update

- Most Society operations are still virtual
- New process for coming back together in-person will be finalized in June
- June 17 Group Leadership Call will include additional training and communication
- Begin polling group members to determine comfort level for in-person meetings and check in with venue
- Continue to meet virtually

Need Support Connecting Your Group?

Resources are Available!

- Skype
- Zoom
- FaceTime
- Google Hangout
- Facebook Messenger
- Free Teleconference Tools
- Support Group finder on Society Website

Connect with your Society Staff Partner to discuss your needs

Self-Help Group Meeting Disclaimer

The National MS Society respects the rights of people with MS to obtain any and all information they want related to MS including information on wellness, medical treatments or complementary therapies, products and services. The information presented at this meeting does not necessarily reflect the views or official position of the National Multiple Sclerosis Society, nor carry the endorsement or support of the Society.

To protect your privacy and the privacy of other members, please do not record, take screenshots, or share information about other members of this group outside of this meeting. For specific medical advice, contact your physician. For the opinion of the National Medical Advisory Committee of the National MS Society on any therapy, treatment or product, please contact your chapter at 1-800-344-4867 (1-800-FIGHT-MS), or visit our website at nationalMSSociety.org



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Virtual Programming

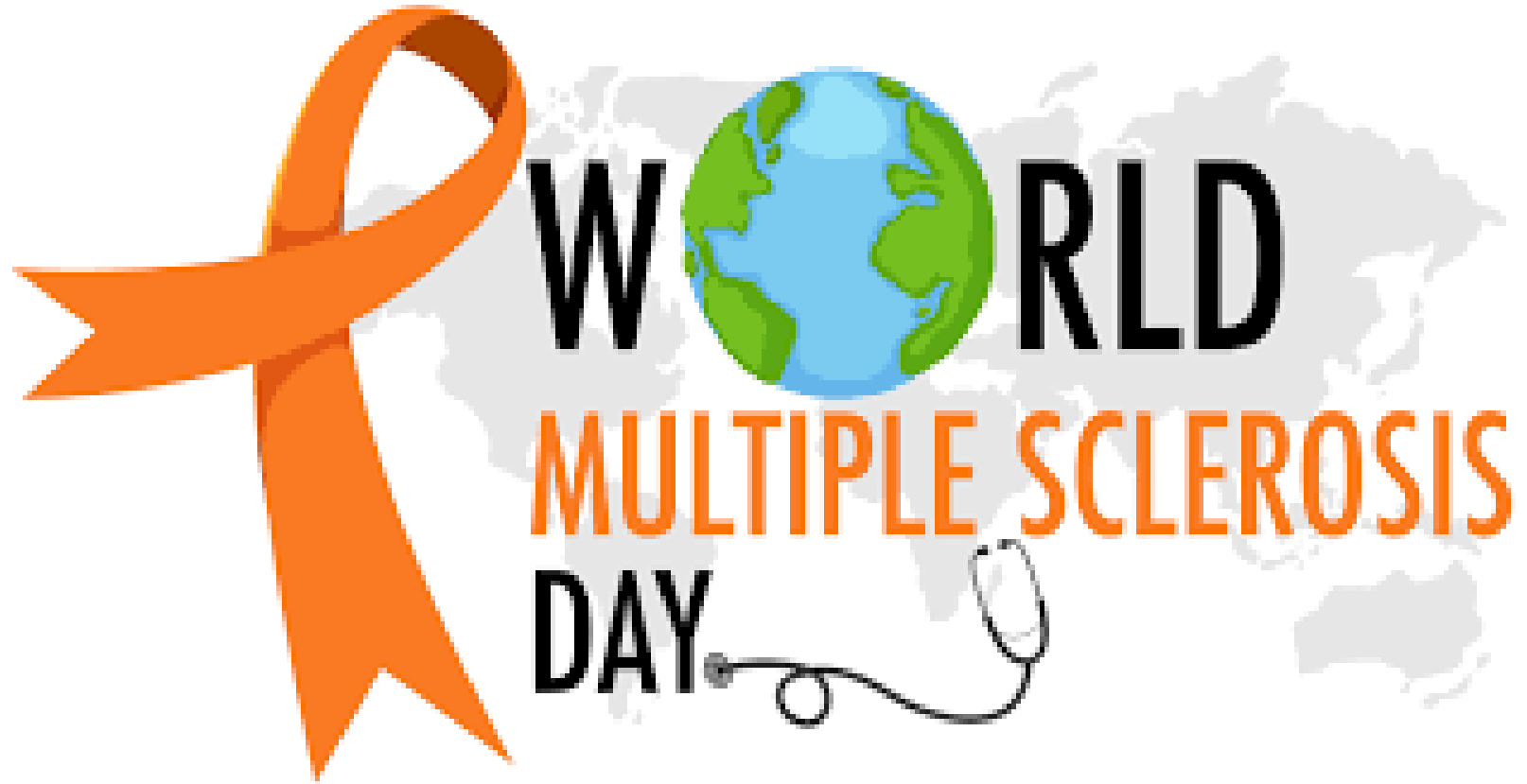
Ask an MS Expert Program Series

- Weekly on Fridays from 1-2pm ET in English
- The 3rd Wednesday of each month from 7-8pm ET in Spanish
- Quarterly for Veterans

May 21: Latest in COVID-19 & MS. Join us and Dr. Nancy Sicotte, Chair of the Society's National Medical Advisory Committee, as we talk about COVID-19 in the pediatric population, vaccine recommendations for people living with MS, and how to continue to protect yourself and others.

WORLD MULTIPLE SCLEROSIS DAY

MAY 30, 2021



Resilience: Addressing the Challenges of MS

- Hosted virtually across the country on a variety of dates
- FREE to attend
- Register at www.nationalMSSociety.org/resilience



Pathways to Wellness

- Thursday, June 10, 2021
- 1 p.m. – 4 p.m. ET/10 a.m. – 1 p.m. PT
- FREE to attend
- Register at www.nationalMSSociety.org/pathways





- June 15 – Navigating the Impact of MS: My Experience with My Parent’s MS
- July 20 – Engaging in the Movement to End MS: Ways Teens Can Be Involved with the MS Society
- August 17 – Increasing MS Awareness
- September 21 – Topic TBD

For more information or to register, visit nationalMSSociety.org/camp



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Stay Connected

Connecting Leaders to Leader

- What questions do you have?
- What questions are you getting from others?
- What resources or support would be helpful?
- Share helpful tips for other leaders.

Connect with the National MS Society



facebook.com/nationalMSsociety



instagram.com/MSsociety



twitter.com/MSsociety



youtube.com/nationalMSsociety



[linkedin.com/company/
national-MS-society](https://linkedin.com/company/national-MS-society)

2021 Monthly Leadership Call Dates

Third Thursday of the month at
3 pm EST and 7 pm EST

- June 17
- July 15
- August 19
- September 16

