

National Multiple Sclerosis Society

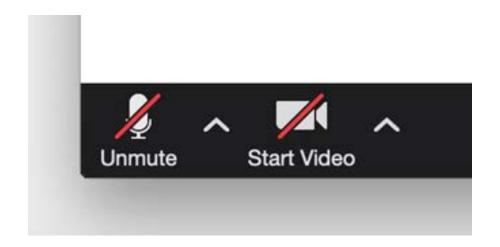
# **Group Leadership Call:** October 20, 2022



Hosted By:
Sarah MacIsaac
Manager, Community Engagement

### **Zoom Tips: Microphone and Camera**

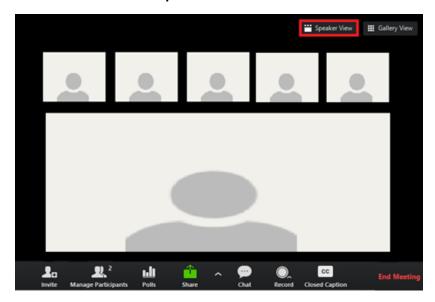
Click the microphone icon to unmute yourself and click the video icon to share your video



### **Zoom Tips: Viewing Options**

Choose what works best for you using the button in the top right corner of your screen

**Speaker View** 



**Gallery View** 



### **Today's Call**

- Announcements & Reminders
- Society Presentations:
  - Advocacy: Steffany Stern, Vice President, Advocacy & Policy
  - Open Enrollment: Carla Turechek, MS Navigator
- Leader Resources

# Vision & Mission Statements

### **Our Vision:**

A World Free of MS.

### **Our Mission:**

We will cure MS while empowering people affected by MS to live their best lives.

# Diversity, Equity and Inclusion

- 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 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 vision.





TRACEY (R)

DIAGNOSED IN 2009



### Inclusion Policy

At the National MS Society, we are committed to embedding diversity, equity and inclusion in everything we do, and we have zero tolerance of any ill treatment towards any person in the MS movement.

#### Everyone who shares our vision of a world free of MS is welcome here. Hatred is not.

This work is a journey requiring commitment, accountability, transparency and courage. We know it will not be easy, but we are going to do it anyway. We are not striving for perfection, only intention and action as we move forward. We extend grace and empathy to everyone who wants to join us on this journey of learning, growth and change. However, we will not tolerate acts of harassment and discrimination.

The National MS Society is here for **every** person with MS — we always will be — until we find a cure. We embrace and are committed to bringing our entire MS community together, representative of all the dimensions of diversity, so that everyone feels at home and supported by their National MS Society.

### Ask an MS Expert

- Weekly on Fridays at 1pm ET /12pm CT/11am MT/10am PT
- Monthly on the 3rd Wednesday of each month in Spanish
- Quarterly for Veterans

### Live stream platforms:

- Facebook <a href="https://www.facebook.com/nationalmssociety/">https://www.facebook.com/nationalmssociety/</a>
- YouTube <a href="https://www.youtube.com/user/NationalMSSociety">https://www.youtube.com/user/NationalMSSociety</a>
- Twitch <a href="https://www.twitch.tv/mssociety">https://www.twitch.tv/mssociety</a>

For more details: <a href="https://www.nationalmssociety.org/MSExpert">www.nationalmssociety.org/MSExpert</a>



### **COMMUNITY PROGRAMS**

Presented by Can Do MS



#### Join the brightest MS pros and the most positive MS warriors

#### Webinar Wednesdays

One-hour, online webinar presented by leading professionals in MS care.

Listen in, ask questions, and stay up to date on research and best practices.

Learn More

#### Your Questions Answered

One-hour, virtual Q&A to help you with your specific questions around common MS topics.

Come prepared with your question or drop in to hear FAQs from the community.

Learn More

#### JUMPSTART ®

Two-hour virtual sessions to meet with Can Do Coaches and your peers.

Learn new skills and connect with other people living with MS for motivation, accountability, and idea-sharing.

Learn More

#### Coaching Series

Four-part virtual group meetings to set goals, learn new skills, and stay motivated.

Connect with a small group of people with MS, receive advice from Can Do Coaches, and find support to address your challenges.

Learn More

CanDo-MS.org/CommunityPrograms or (800) 367-3101





www.nationalmssociety.org/Resources-Support/Find-Support/Online-Communities





<u>www.nationalmssociety.org/Resources-Support/Library-Education-Programs/Hispanic-Latinx-MS-Experience-Summit</u>



#### Recorded breakout sessions included:

 MS Diagnosis in the Black MS Community, Understanding Clinical Trials & Studies, Removing the Stigma of Mental Health Services, Challenges that Impact MS Care, Nurturing Your Emotional & Spiritual Health, Managing Long-Term Outcomes, Understanding Treatment Goals, and Exploring Complementary & Alternative Treatments.

www.nationalMSsociety.org/blackMSexperience





National Multiple Sclerosis Society

### **MS Activism**

Steffany Stern
Vice President
Advocacy and Policy

### Advocacy and the Society 101

- MS Activists speak with one clear voice to advance federal and state policies that improve the lives of people impacted by MS
- Lawmakers listen to constituents!
- There are many ways to engage



### Inflation Reduction Act



- Inflation Reduction Act Advocacy
  - 1,028 advocates
  - 2,990 message sent

## Inflation Reduction Act

- \$2,000 out-of-pocket cap for Medicare prescription drugs, and the ability to spread those cost throughout the year
- Limiting price increases of medications to the rate of inflation
- Medicare negotiation for a limited number of medications long on market
- Greater assistance for people with lower incomes on Medicare
- Extension of tax credits to make marketplace plans more affordable





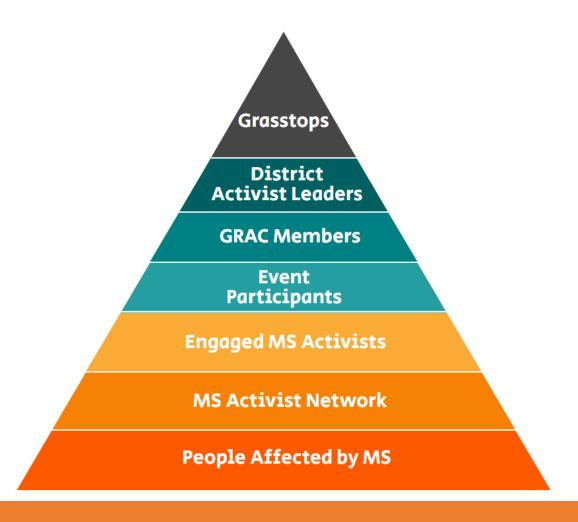






**Together We Are Stronger.** 

### MS Activist Ladder of Engagement





### MS Activist Network

- Join MS Activist Network!
- We'll contact you when we need you to act
- We'll provide the details, you share your story

Follow @MSActivist on Twitter

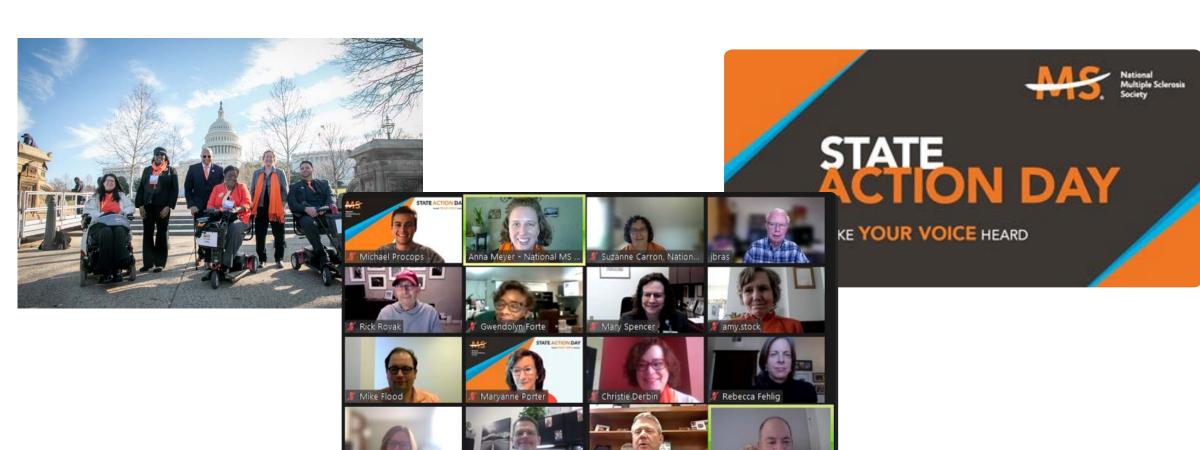
# Text MSActivist to 52886

To join the MS Activist network

www.nationalmssociety.org/msactivist



### **Advocacy Events**



# District Activist Leader Program

- Build relationships with members of Congress
- Engage officials on Society's federal policy priorities
- Year-round commitment
- •No experience needed!
- Training and support provided by Society staff



# Questions?

www.nationalmssociety.org/msactivist

Follow @MSActivist on Twitter

Text MSActivist to 52886

To join the MS Activist network



Steffany Sterns
Steffany.Sterns@nmss.org





National Multiple Sclerosis Society

### Open Enrollment Support for Self-Help Group Leaders

MS Navigator Experience
Benefits, Employment, and Health
Insurance Support Team
October 2022



# What is Open Enrollment?

Open enrollment is a period during which one may freely enroll in or change one's selection of a health insurance plan or other benefit program that is ordinarily subject to restrictions.



### Dates & Deadlines

Job-based	Marketplace	Medicare
Varies	Begins November 1	Begins October 15
Often occurs in the fall	Ends January 15	Ends December 7
	Enroll by Dec. 15 for Jan. 1 coverage	





- MS Navigators provide Open Enrollment information and referrals
- The Benefits, Employment, & Health Insurance Support Team provides
   Medicare Open Enrollment consultations

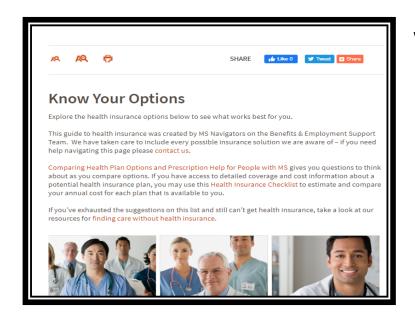


**Angela, MS Navigator** 



 Ask an MS Expert program series covering Open Enrollment

### Online Self-Service Resources



www.nationalmssociety.org/openenrollment

www.nationalmssociety.org/rxhelp

www.nationalmssociety.org/getcovered

### Printable Resources

Medicare Resources for People with MS

Application Checklist for the Health Insurance Marketplace

Comparing Health Plan Options and Prescription Help For People with MS

Available in English and Spanish

# Connect with MS Navigators and the Benefits, Employment, & Health Insurance Support Team

800-344-4867

7:00am to 5:00pm MT, Mon-Fri

ContactUsNMSS@nmss.org

Social Media and Online Chat





National Multiple Sclerosis Society

### Leader Resources

# November – National Veterans Month

#### **Veterans & MS website**

 https://www.nationalmssociety.org/Resources-Support/Find-Support/Veterans-with-Multiple-Sclerosis

### Nationwide, Virtual Group for Veterans

https://www.nationalmssociety.org/Chapters/FLS/Groups-and-Discussions/Programs/Veterans-Self-Help-Group

### **Quarterly Ask an MS Expert for Veterans**

• <a href="https://www.nationalmssociety.org/Resources-Support/Library-Education-Programs/Ask-an-MS-Expert-Program-Series">https://www.nationalmssociety.org/Resources-Support/Library-Education-Programs/Ask-an-MS-Expert-Program-Series</a>

### Together, we can ensure that veterans with MS live their best lives

The National MS Society partners with the VA MS Centers of Excellence to offer a multitude of resources to veterans and their providers:



#### FOR VETERANS

- MS Navigator services that offer personalized information, resources, and create a lasting solution to the unique and complex challenges of living with MS. Email contactusnmss@nmss.org; call 1-800-344-4867; or live chat at nationalMSsociety.org
- Current information about Society programs available online and in person through ntlms.org/veteran; or email contactusnmss@nmss.org
- Comprehensive information about MS and treatment ntlms.org/overview; call 1800-344-4867 for more information; or email contactusnmss@nmss.org

#### FOR HEALTHCARE PROFESSIONALS

- Access to collaborative, quarterly CME webinars on MS clinical challenges ntlms.org/resources
- National MS Society Professional Resource Center nationalmssociety.org/ For-Professionals
- Current information about resources for your patients ntlms.org/patients



For more information visit: ntlms.org/VAbenefits OR va.gov/MS



# November – National Family Caregivers Month

### **Carepartner website**

 https://www.nationalmssociety.org/Living-Well-With-MS/Relationships/Family-Matters/Carepartners

### **Carepartner & Caregiver Groups**

 Virtual & In-Person groups exist across the country- connect with your Staff Partner for information in your community



National MS Society Phone: 800-344-4867

Website: nationalmssociety.org/Living-Well-With-MS/Relationships/Family-Matters/Carepartners

#### One-on-One Peer Connections

**Description:** The MSFriends program connects you with volunteers affected by MS. Connect with a peer support volunteer who has "been there" and can provide you with helpful tips, suggestions and emotional support via phone or email.

Website: nationalMSsociety.org/Resources-Support/Find-Support/Connect-with-Peers-One-on-One

#### Care.com

Services: Offers referrals to care providers and a library of articles about care & caregiving.

- Care for Seniors: Search for assisted living, home care, adult day health, independent living, and transportation needs.
- Care for Pets: Search for pet sitting, walking, day care, boarding/kenneling, training and grooming.
- Care for Your Home: Search for a personal assistant, housekeeper, or house cleaner.

**Description:** Care.com's mission is to improve the lives of families and caregivers by helping them to connect in a reliable and easy way. Care.com's solutions help families make informed decisions in one of the most important and highly considered aspects of their family life: finding and managing quality care for their loved ones. Articles are available for free on the site; however, use of the "find care" tool requires a paid membership. Monthly and annual subscriptions available. Browse for care, jobs, articles and more using the Care directory.

Phone: 877-227-3115 Website: care.com

#### Caregiver Action Network

Services: Caregiving advice, support, and information; includes forums, e-newsletters, and a network of volunteers.

**Description:** The Caregiver Action Network (CAN) is a leading non-profit family caregiver organization that works to improve the quality of life for the more than 90 million Americans who care for loved ones with chronic conditions, disabilities, disease, or advancing age. CAN provides education, peer support, and resources to family caregivers across the country free of charge. Visit the site to join CAN for free, view the Family Caregiver Toolbox, or view additional caregiver resources (by topic).

Phone: 202-454-3970 Website: caregiveraction.org

#### Caregiver.com / Today's Caregiver Magazine

Services: Provides information, support, and services referrals. Also offers a magazine, newsletters, and online forums.

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### **Group Promotional Resources**



Grassroots Marketing Resources for Self Help Group Leaders

As you know your community best, the Society has developed promotional resources for you to use when marketing your group to local entities. We encourage you to review this list and work directly with your Staff Partner to develop a marketing plan that works best for your group and your community.

#### Things to Consider:

- When listing your contact information for the group on promotional materials, are you comfortable using your personal email address, home phone number and/or cell phone number? Are you open to receiving text messages?
  - If you are not comfortable using your personal information, we recommend creating a free email
    account that is group specific and checking that account frequently (i.e. <u>TownMSGroup@gmail.com</u>,
    <u>Men&MSGroupTown@hotmail.com</u>).
- Group Leaders can also encourage group members to assist with grassroots marketing based on relationships they have with community entities listed above.
- The Society does have funds to support printing costs for group marketing. Work with your Staff Partner to learn more about our reimbursement policy and how to access this support.
- When sharing promotional materials, make sure you secure the proper permission prior to posting. Entities may
  have a process in place for approval and may have time limits for approved postings.

#### **Optional Promotional Resources**

- Promotional Flyer: Your Staff Partner can create/update your group specific flyer for grassroots marketing within
  your community. Once finalized, your Staff Partner can email you a PDF version of the flyer for electronic
  sharing and for local printing & hard copy distribution.
- Business Cards: Your Staff Partner can create/update the Society's Group Leader Business Card template with
  your information.
- Support Letter for Sharing Flyers: This letter template can be used when emailing your flyer and/or when
  dropping off hard copy flyers to introduce yourself and your group to new relationships. You can use the letter
  as is or adjust it to fit your needs. The text can be used for letters, notecards, and/or emails based on the
  outreach method you are using.

#### **Grassroots Recommendations**

Based on your local community, potential grassroots marketing locations to share promotional materials can include:

- Medical: Partners in MS Care Centers, Neurology offices, Rehab (PT/OT/SLP) offices, infusion centers, Chiropractic offices, Home Care agencies
- Wellness: YMCAs, YWCAs, local fitness centers/gyms
- Community Based: community centers, town/city website calendars and/or newsletters, supermarket
  community boards, library community boards, church/synagogue bulletins, mental health offices, assisted living
  facilities, senior centers
- . Social Media (OPTIONAL): town/city/community Facebook groups, personal postings on social media platforms
  - o \*It's important to recognize that a leader sharing their group promotional information to a town/city/community Facebook group will likely be required to use their personal Facebook account to post to any Facebook community groups they are a member of. Leaders need to be aware of the disclosure potential for a larger audience to see their post and should a leader NOT be comfortable with this level of sharing, it is perfectly ok to not use social media to promote the group.



#### Sample Group Name

2<sup>nd</sup> Tuesday of each month, 7-8pm Your Local Library Main Street, Your City, US

The National MS Society maintains a network of affiliated groups to provide opportunity for people living with MS to connect with others in their community. Every group is unique and welcoming — contact the group leader(s) for more information.

#### Join Us!

For information or to RSVP, contact:

Your Name, phone number Your Co-Leader Name, group email address

For more information, call 1-800-344-4867 or scan the QR code





### **NEW Community 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 shared during community connections does not necessarily reflect the views or official position of the National Multiple Sclerosis Society, nor carry the endorsement or support of the Society.

By choosing to participate in National MS Society-governed self-help groups, MSFriends® paired connections, and social media and online communities, you are agreeing that the Society can contact you directly in response to any posts or content that suggests risk to self and/or others. The Society reserves the right to contact you in the event that "at risk" statements or content occur.

To protect your privacy and the privacy of others, please do not record, take screenshots, or share personal information with anyone other than your staff partner.

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 an MS Navigator at 1-800-344-4867 or visit our website at <a href="https://www.nationalMSsociety.org">www.nationalMSsociety.org</a>



https://www.facebook.com/groups/connectionsvolunteers/



### Peer Connections Volunteer Website

#### www.nationalMSsociety.org/peerconnectionsvolunteers



in Person



#### Peer Connections Volunteers

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

NEW: View our Resources for Meeting in Person



- Grassroots Marketing Resources for Group Leaders
- Community Disclaimer for Peer Connections Participation
- > Community Disclaimer for In Person Self Help Group Meetings
- Active Listening
- > Volunteer Code of Conduct
- > Difficult Conversations & Crisis Support
- Disability Language and Etiquette
- > Diversity, Equity and Inclusion Statement & Inclusion Policy
- Medical Advice & Medicine Sharing
- > MSFriends Conversations Quick Guide
- MSFriends Establishing Boundaries
- Non-National MS Society Relationships FAQ
- Solution Focused Conversations
- > Tips for Hosting Virtual Online and In-person Groups
- Virtual Meeting Resources

**Together We Are Stronger.** 



### In Person Meeting Resources

### **Key Takeaways from current Society Guidelines:**

- Vaccines: encouraged, but not required
- Masks: optional for indoor & outdoor gatherings

#### Web Resources:

- FAQ Resource Document (PDF)
- National MS Society Self-Help Group Safety Flyer (PDF)
- Community Disclaimer for In Person Self Help Group Meetings (PDF)

### **Connect with the National MS Society**



facebook.com/nationalMSsociety



instagram.com/MSsociety



twitter.com/MSsociety



youtube.com/nationalMSsociety



linkedin.com/company/ national-MS-society

# Thanks for joining us!

