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National
Multiple Sclerosis
Society

75

YEARS OF **PROGRESS**

Group Leadership Call: August 19, 2021 3PM EST



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

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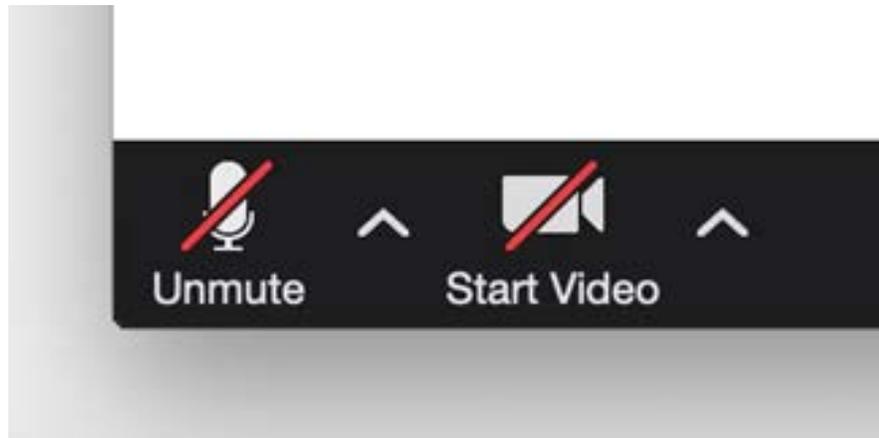
Group Leadership Call: August 19, 2021 7PM EST



Hosted By:
Sue Pandya
Manager, Community Engagement
Phoenix, AZ

Zoom Tips: Microphone and Camera

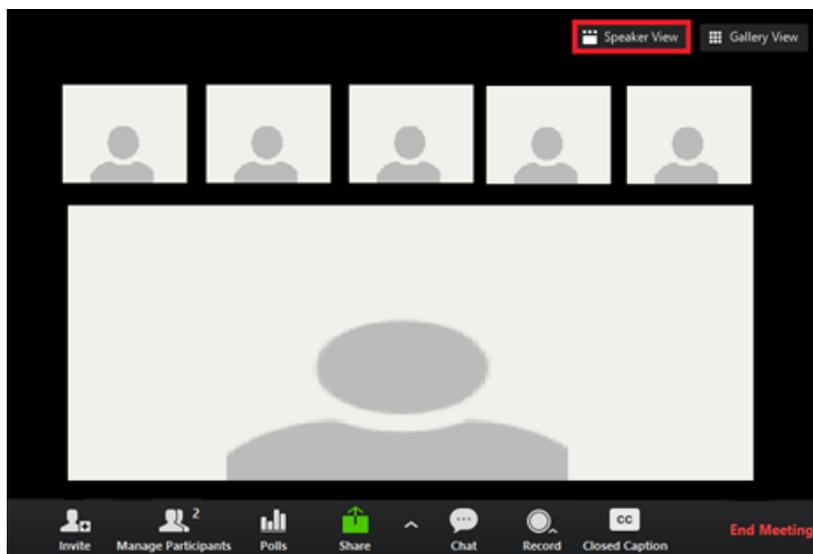
Click the microphone icon to unmute yourself and click the video icon to share your video



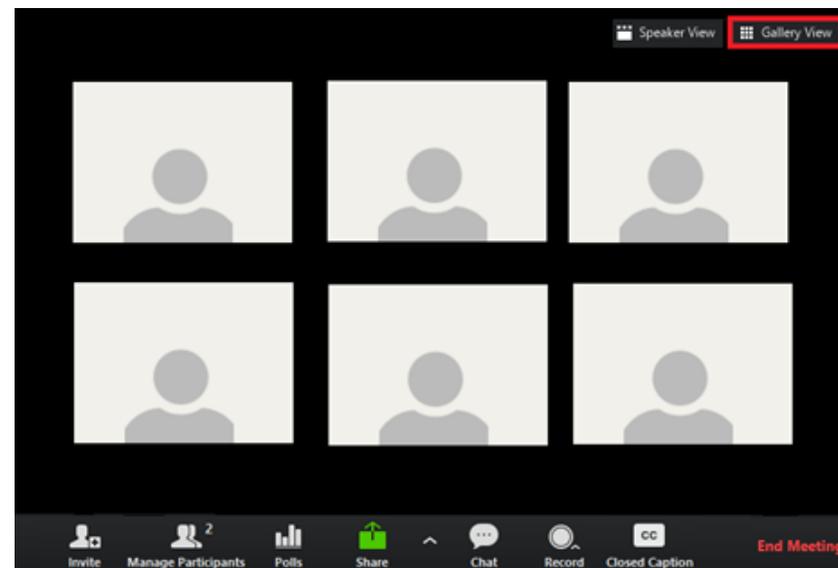
Zoom Tips: Viewing Options

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

Speaker View



Gallery View



Today's Call

- Program Reminder: Black MS Experience programs
- Presentation: Group Meetings with Sarah MacIsaac and special guests Veronica Daniels – Lewis, Support Group Leader from Houston, Texas.
- Society and Leader Resources
- Questions, Feedback, and Discussion

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.

Black MS Experience Programs



Black MS Experience

Black people living with MS encounter unique stressors, challenges and experiences. Through content, videos and discussions on a variety of topics related to navigating and overcoming challenges in daily life with MS, this program offers a safe space to raise awareness and forge connections to help Black individuals living with this disease be seen and understood.

Register for a [group discussion](#) below. Discussions are hosted online and available to anyone regardless of location. Check back as more program dates will be announced.

The Black MS Experience Program Series will cover topics such as:

- › **Health Disparities:** Address health disparities and solutions to move forward.
- › **Black MS Research: Clinical Trials:** Share clinical trial experiences and learn how to leverage community strengths to educate the Black MS community.
- › **Mental Health:** Discuss mental health challenges and actions to enhance personal wellness.
- › **Wellness:** Discuss strategies to manage your physical, emotional and social wellness.
- › **Advocacy:** Share how you can advocate for change and build awareness.

Black MS Community Group Discussions:

- August 21: New York City & Detroit
- August 24: Philadelphia
- August 25: Atlanta
- August 28: North & South Carolina

Black MS Experience Summit

- September 22-23
- Registration is now open!

www.nationalmssociety.org/BlackMSExperience

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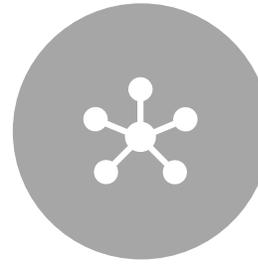
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Group Meetings: Agendas, Speakers & Education

How Groups Help



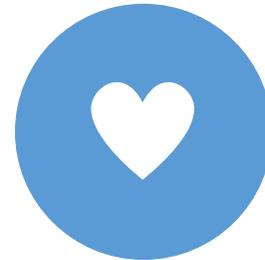
LISTENING



**SHARE
INFORMATION**



**SHARE
RESOURCES**



**EMOTIONAL
SUPPORT**



**PERSONAL
EXPERIENCE**

Group Leader Toolkit Resources



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 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 the Society at 1-800-344-4867 (1-800-FIGHT-MS), or visit our website at nationalMSSociety.org.

As a participant in this meeting, you've agreed to follow our safety protocols and understand that if not fully vaccinated, wearing a mask is required. As a participant, you are also agreeing that you understand the contagious nature of COVID-19 and assume all risk associated with attending meeting, including being exposed to COVID-19, and, as a participant, waive the National Multiple Sclerosis Society from all liability therewith.



Medical Advice

Support group leaders do not give medical advice.

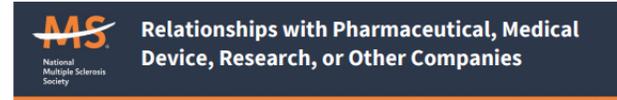
In their role with the National MS Society, group leaders do not offer medical advice even if they are healthcare professionals by trade. Group leaders and members may share information on personal experiences, treatments, etc., but refrain from giving personal interpretations, giving advice, sharing medication, or offering recommendations.

In order to help ensure that advice is not given by group members, group leaders share group guidelines at all meetings, monitor discussions and lead the group process.

Medicine Sharing

Support groups do not engage in sharing or swapping medicines of any kind.

For liability reasons, National MS Society staff and volunteers cannot get involved in any swapping or sharing medicines among group members. Many prescription medicines are controlled substances and FDA regulations do not permit sharing medicines among patients because the safety and efficacy of shared medications cannot be ensured. Therefore, group leaders must not permit the practice or communication of shared medications to happen during any Society group meetings.



Relationships with Pharmaceutical, Medical Device, Research or Other Companies: Frequently Asked Questions

There are times when a pharmaceutical company sales representative contacts me, the support group leader, directly and offers to arrange for speakers and refreshments for upcoming meetings. Is this an acceptable practice?

No, it is not. It is the responsibility of Society staff to explain to their pharmaceutical and medical device companies that representatives are not to directly contact and support the Society's support groups.

Pharmaceutical and medical device sales representatives may find and fund speakers for support group meetings, as well as pay for and provide refreshments. Your Society staff partner is to coordinate these types of requests and should approve of the speaker and proposed content first. When introduced, the speaker must fully disclose that he/she has been paid an honorarium by the pharmaceutical company. If the speaker plans to use handouts provided by the company, the Society must review the handout in advance. The pharmaceutical or medical device sales representative is not allowed to be present at the meeting.

If a pharmaceutical or medical device company sales representative contacts you directly with a request to bring in a speaker and/or provide food and refreshments for a meeting, please refer the request to your staff partner and let the representative know you have done this.

My support group has a situation where a pharmaceutical company sales representative attends each meeting, providing snacks, befriending members, etc. She is genuinely liked and appreciated by the group members. Is it okay for her to attend the meetings?

While the sales representative may be a genuinely caring and generous person, her presence at the support group is ultimately to promote her company's product. This goes against Society policies, in some cases against the pharmaceutical company's policy, and it

www.nationalMSSociety.org/PeerConnectionsVolunteers

Building & Using Agendas

Example 1:

- Welcome to our group!
 - Disclaimer
 - Diversity, Equity & Inclusion
- Round robin check in & member updates
- Conversation topic:
 - Heat- how's everyone doing?
- Next month: reminder of guest speaker, conversation topic, schedule updates, etc.



Example 2:

- Welcome!
 - Disclaimer
 - Diversity, Equity & Inclusion
- Guest Speaker: (include name & bio)
 - Include time for Q&A with speaker
- Open discussion
- Wrap Up and News to Know for Next Month

Guest Speakers

Identifying potential speakers:

- Group members as community resource- who do THEY know?
- Connect with other group leaders in your area- who do THEY know?
- Connect with your staff partner to **brainstorm** appropriate types of speakers on topics and to potentially identify community providers/agencies that might be a good fit
- Not all speakers are appropriate for groups

Once a speaker is identified:

- Reach out and ask!
- Be flexible on dates offered
- If virtual or hybrid- speakers don't need to be local
- Confirm with speaker a few days prior to scheduled visit



Educational Resources

Educational Resources & Toolkits

For Peer Connections Volunteers

- Resources for Peer Connections Volunteers
- Group Leadership Call Recordings
- Educational Resources & Toolkits
- Resources for Meeting in Person



SHARE



This page includes videos, materials & toolkits on a variety of topics to support group learning. Virtual & in-person materials and resources are included.

Resources

- National MS Society Brochures – The Society's online library of free downloadable resources & brochures.
- Ask an MS Expert program series – Weekly webinar to learn more about multiple sclerosis from top MS experts.
- Webinar Series with Can Do MS – Upcoming live webinars to share with group members or watch as a group
- On Demand Educational Videos – Share with group members or watch as a group
- RealTalk MS – Get the latest news about MS through a weekly podcast.
- Facebook National MS Society Community page
- National MS Society YouTube channel
- MS 101 Webinars
 - Pediatric MS
 - Cognition in MS
 - Pain Management
 - Risk Factors and Prevention of MS
 - MS in the African American Population
 - Exercise and MS

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- Ask an MS Expert: Aging and MS**
672 views • Streamed 6 days ago
- Lunch Guarantors**
Carey and Cheryl Cooper
Phillip and Sandra Cooper
The Pivar/Taussig MS Fund
1:32:16
- MS Society Cohn Weil Gamesday**
366 views • Streamed 1 week ago
- Ask an MS Expert: Is it MS or Something Else?**
730 views • Streamed 1 week ago
- Cohn Weil Young Professionals Summer...**
139 views • 1 week ago
- Game Night For The MS Fight**
252 views • Streamed 3 weeks ago
- Pregúntale A Un Experto en Esclerosis Múltiple: Lo...**
114 views • 3 weeks ago
- Getting Started with Your Healthy Lifestyle**
222 views • 3 weeks ago
- MS Wellness Research**
411 views • 3 weeks ago
- Panel Q&A**
96 views • 3 weeks ago
- Wellness Through Exercise and Lifestyle Physical...**
100 views • 3 weeks ago
- Ask an MS Expert: Managing MS Relapses**
563 views • Streamed 3 weeks ago

<https://www.youtube.com/nationalmssociety>

Guest Leaders

- Special guest(s) Veronica Daniels – Lewis from from the Sugar Land SW, Houston, Texas SHG

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Society & Leader Resources

Peer to Peer Connection Opportunities



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
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*

Research Opportunity

- **CONNECT e-trial information**

- Society funded trial to share with your group members!
- 12-week professionally-led online support group focused on Black & Latinx individuals living with MS
- If you, or your group members, are interested in finding out more information on this trial, additional details will be in next week's Group Leader Newsletter

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

Vaccine Use in MS and COVID-19 Update **Friday, August 20 | 1:00 PM EDT – 2:00 PM EDT**

Many people living with MS have concerns about the safety of routine vaccinations and currently more so about the COVID-19 vaccines. Join us and Dr. Nancy Sicotte, Chair of the Society's National Medical Advisory Committee, as we talk about vaccine-preventable infections and vaccine recommendations for people living with MS. We will discuss COVID-19 updates and share the most accurate and reliable guidance possible to help everyone with MS make informed decisions and feel connected and supported. Also, Victoria Holmes, nurse practitioner who lives with MS, will share her story and personal experience with the COVID-19 vaccine.

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

2021 Monthly Leadership Call Dates

Third Thursday of the month



September 16

October 21

November 18

December 16

3 pm EST and 7 pm EST