



National
Multiple Sclerosis
Society

Connections Volunteers Drop-In Call

December 3, 2020



Desiree Schnoor
Manager
Community Engagement

The screenshot shows the GoToMeeting interface for a 'SHGL Drop-in Calls' session. The top bar includes the GoToMeeting logo, a 'REC' indicator, and window controls. Below the bar, there are icons for participants (1), chat, and settings. A participant card for 'Wenda Carlson' (WC) is visible. Annotations with arrows point to the chat icon and the settings gear icon. The settings menu is open, showing options for 'Mute', 'Camera', 'Screen', and 'Leave'. The 'Mute' option is highlighted with a red circle.

Open Chat box

Camera and Audio settings
Audio options: **1)** Select 'Computer' to use computer mic, or headset with mic plugged into computer, or **2)** Select 'Phone' and dial number shown on screen with access code and audio pin

Mute/Share webcam/Leave

Mic Camera Screen Leave

Q&A: There will be time for questions after presentation

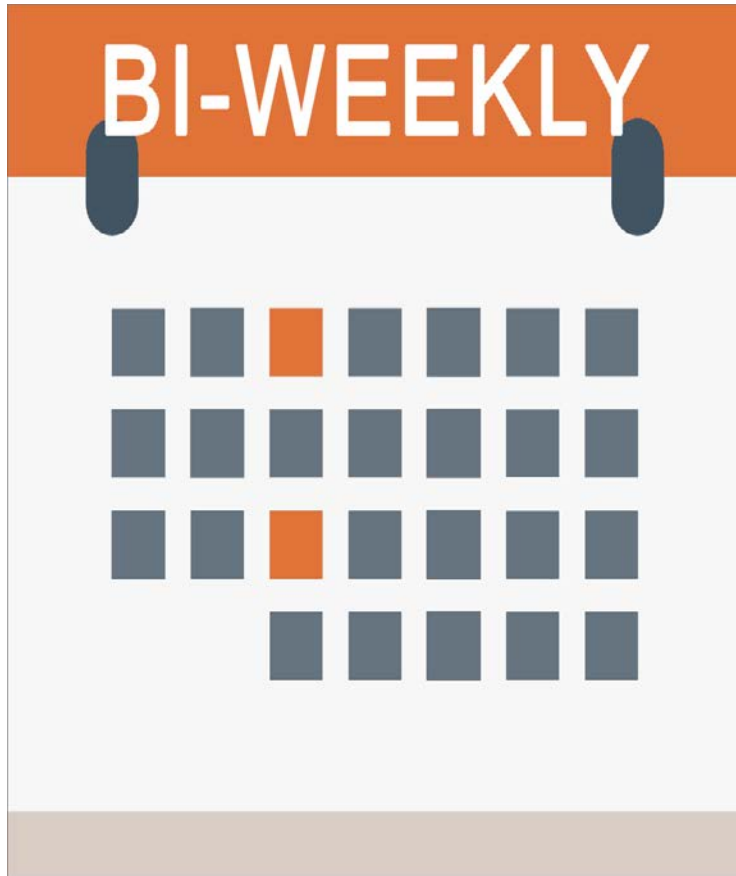
- Option #1: Pop on camera using your webcam; unmute
- Option #2: Type your question in the Chat box

A recording of this call (without webcam) will be posted on our website at:
<https://www.nationalmssociety.org/Resources-Support/Find-Support/Connect-with-Peers-One-on-One/For-Connection-Program-Volunteers>

Today's Time

- **Reminder:** We are extending our virtual format into the new year. Stay tuned for updates.
- Open Enrollment and Marketplace Insurance deadlines
- We are here to support you! - New support email: peerconnections@nmss.org
- Connections Program Volunteer Website: <http://nationalmssociety.org/ConnectionsVolunteers>
- Questions/Feedback/Discussion

Bi-Weekly Ongoing Drop In Call Dates



- December 3rd
- December 17th
- 2021 dates TBD

Support for Leaders and Groups

- **We are going digital through December 31st**
- **Bi-Weekly Ongoing Drop In Calls**
 - Thursdays at noon PST/3EST
 - December 3: Research, Clinical Trial Information
 - December 17: Holiday Party, Depression, Meditation
- **MS Navigators are available to help**
- **Find Doctors and Resources Online**



**National
Multiple Sclerosis
Society**

Kathy Zackowski, PhD, OTR

Research update

Mission and Vision

Mission statements define why an organization exists and vision statements outline the future the organization aspires to achieve. Together these statements help build the foundation for a Strategy.

Mission Statement

Why do we exist?

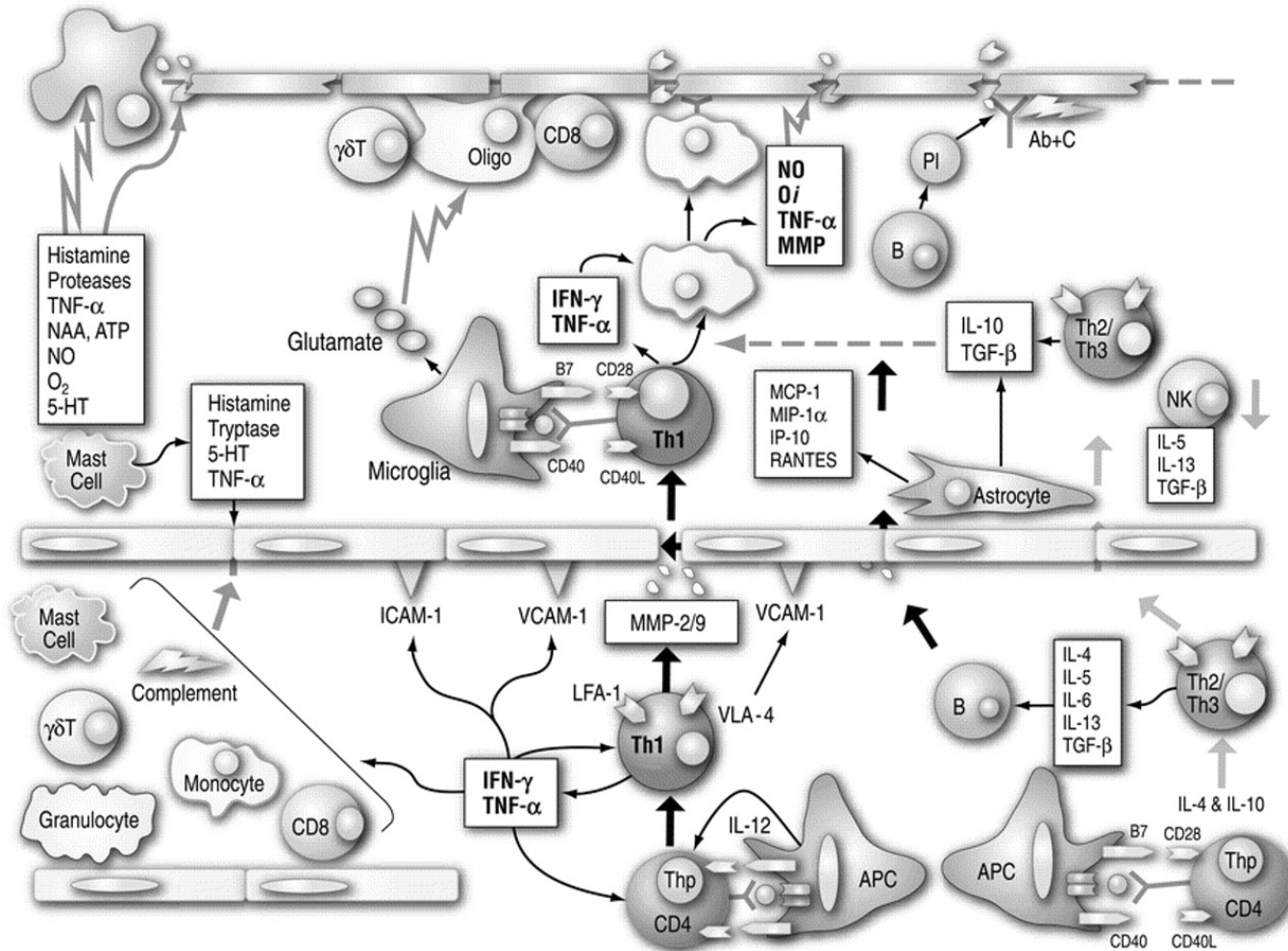
People affected by MS can live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever.

Vision Statement

What future do we aspire to achieve?

A world free of MS.

A complex disease, A comprehensive approach



Clinical trials

- Research study done with humans to discover or verify the efficacy and safety of an intervention.
 - The primary way researchers discover if a new treatment is safe and effective in humans
 - Offer new opportunities for the treatment of disease
 - Follow a specific study plan, called a protocol
 - Have regulatory requirements
 - Drug developers must submit an application to the Federal Drug Administration before beginning

Phases of clinical trials

- Phase 0

- Purpose: to learn how a drug is processed in the body and how it affects the body.
- Size: 10-15 healthy volunteers or people with the disease

Phases of clinical trials

- Phase I

- Purpose: safety and fewest side effects, and dosage
- Size: 20-100 healthy volunteers or people with the disease
- Length: Usually several months

Phases of clinical trials

- Phase II

- Purpose: efficacy (does the drug work) and side effects
- Size: Up to several hundred healthy volunteers or people with the disease
- Length: Usually several months to two years

Phases of clinical trials

- Phase III

- Purpose: efficacy and monitoring of adverse reactions
- Size: 300 to 3,000 healthy volunteers or people with the disease (often participants are randomized)
- Length: 1-4 years

Phases of clinical trials

- Phase IV
 - Purpose: safety and efficacy. Tests new drugs approved by the FDA
 - Size: Several thousand healthy volunteers or people with the disease
 - Length: 1-4 years

Research

- Basic biomedical
- Clinical trials
- Translational
- Rehabilitation
- Wellness

Common wellness themes:



Move More, Eat Healthy



We need data to guide this in multiple sclerosis

eat well
move more
feel better



Wellness

“An active process through which people become aware of and make choices toward a more successful existence.”

(<http://www.nationalwellness.org/?page=AboutWellness>)

Wellness Dimensions



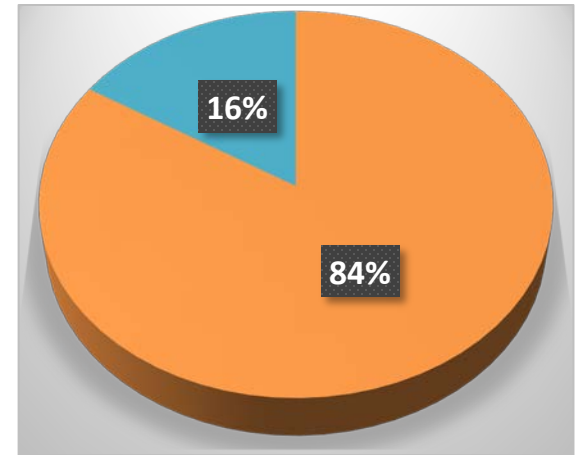
The dimensions of wellness act and interact in ways that contribute to well-being.

They are influenced by health and other factors and involve lifestyle behaviors and activities

Lifestyle and wellness approaches are part of the comprehensive management of multiple sclerosis

Do people with MS use wellness practices?

- Wellness and diet survey*
- 416 respondents
- **84% use wellness practices**
- Top-most used practices:
 - Deep breathing exercises
 - Meditation
 - Massage
 - Mindfulness training
 - Yoga
 - Exercise therapy (Feldenkrais, Pilates, etc.)



* Information courtesy of iConquerMS

Wellness is a high priority for people with MS

- What can I do today to feel my best?
- Will lifestyle interventions impact symptoms?
- Will lifestyle interventions alter the disease course (when combined with conventional approaches)?

Psychosocial wellness

A multi-dimensional domain involving a range of emotions, thoughts, social/environmental factors, and behaviors, including the actions people pursue to regain, maintain, or improve their psychosocial health.

Psychosocial Wellness Subgroup

- Dawn Ehde
- Kevin Alschuler
- Meghan Beier
- Malachy Bishop
- Nancy Chiaravalloti
- Fred Foley
- Abbey Hughes
- Anna Kratz
- Ruchika Prakash
- Angela Senders
- Amy Sullivan
- Nick LaRocca

Objectives:

1. Generate and promote high quality psychosocial wellness science
2. Translate new evidence into practice and programs
3. Provide a network to collaborate and train faculty

Fatigue

- Very common, and very frustrating symptom in MS
- Defined as: The intensity of perceived tiredness, lack of energy, or exhaustion (Lerdal et al., 2005)
- Reflects the experience or the sensation of a lack of energy
- **Fatigability** – reflects how a person fatigues as a result of activity

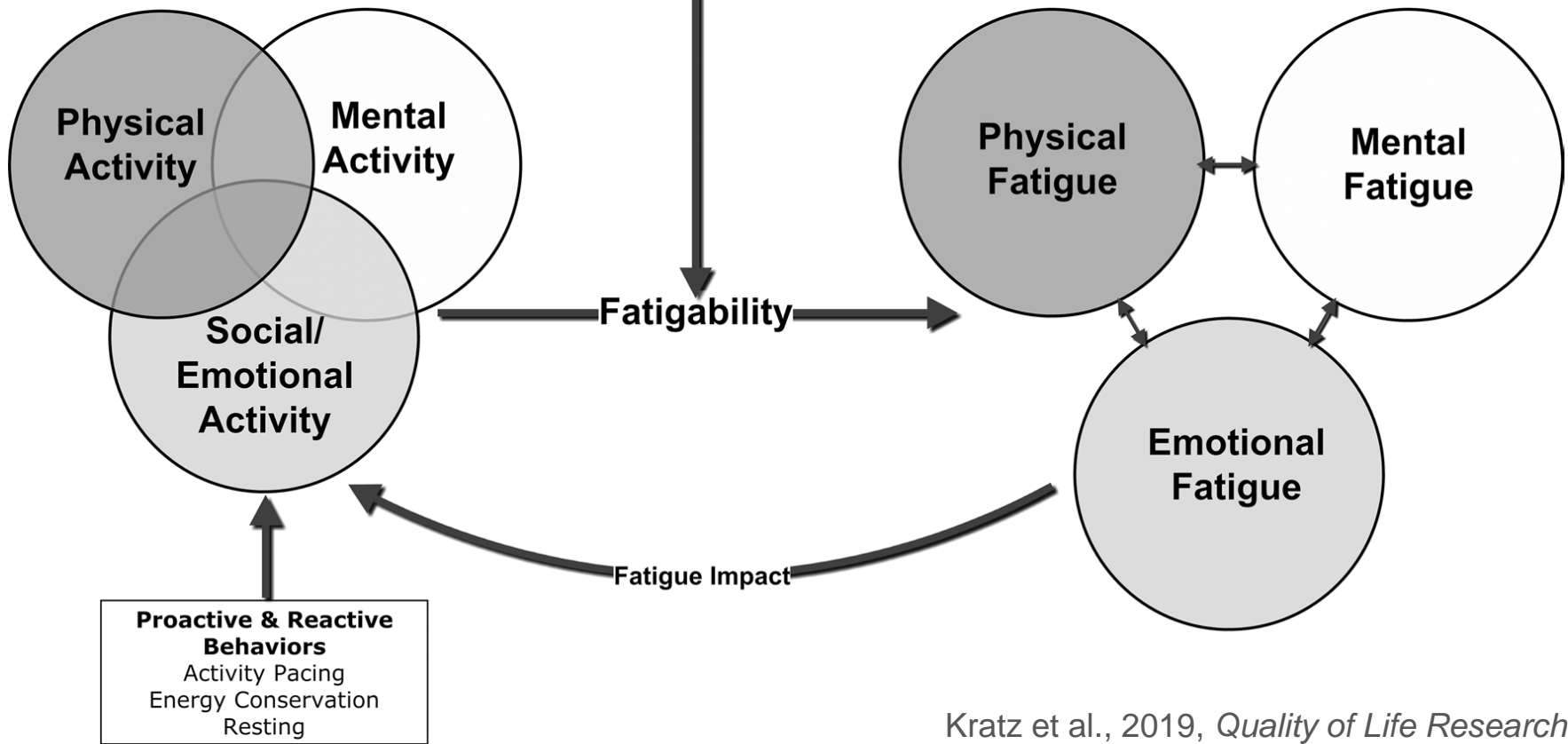
Fatigue

Relatively Variable Moderators:	Relatively Stable Moderators:
Sleep Quality	Sleep Disorders
Interest/Motivation	Physical Fitness
Emotional State	Medications
Diet	Diagnoses/Comorbidity
Weather	Age
Other symptoms (pain)	Personality Traits
Sensory Context (lights/sounds)	Disease Severity
Social Context	
Acute Illness	

Individual differences exist in terms of what activities are fatiguing. This may be because of moderators.

Kratz et al., 2019, *Quality of Life Research*

<p>Relatively Variable Moderators:</p> <ul style="list-style-type: none"> Sleep Quality Interest/Motivation Emotional State Diet Weather Other symptoms (pain) Sensory Context (lights/sounds) Social Context Acute Illness 	<p>Relatively Stable Moderators:</p> <ul style="list-style-type: none"> Sleep Disorders Physical Fitness Medications Diagnoses/Comorbidity Age Personality Traits Disease Severity
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Kratz et al., 2019, *Quality of Life Research*

MS Risk factors

- **Other medical conditions (comorbid conditions)** - increase the risk of getting MS and for existing MS to worsen
- **Smoking** - a risk factor for MS and MS progression
- **Obesity** - a risk factor for developing MS and MS progression
- **Vitamin D**
 - Low vitamin D is a risk factor for the development of MS
 - May be associated with disease progression

J Neurol Neuromedicine. 2016; 1(7): 1–5.
Nature Reviews Neurology 2017;13,25–36

MS and Psychosocial Health: What you can do now

- Exercise regularly and increase your physical activity
- Pace yourself and get enough rest
- Learn more about meditation, deep breathing exercises or mindfulness-based practice, and try them.
- Maintain a healthy diet

MS and Psychosocial Health: What you can do now

- Engage in mentally stimulating activities you enjoy:
 - Reading a book
 - Challenge yourself by learning something new
 - Be socially active
 - Play an instrument or listen to music
- Try to minimize stress and anxiety
- Avoid: smoking, abusing alcohol, misusing prescriptions, etc.

The National MS Society is committed to the study of Wellness

- The Society supports 30 current projects under the category of reversing symptoms or promoting wellness
- These studies total \$9.1 Million
- Some examples of this exciting research follow.

Marcia Finlayson, PhD, OTR

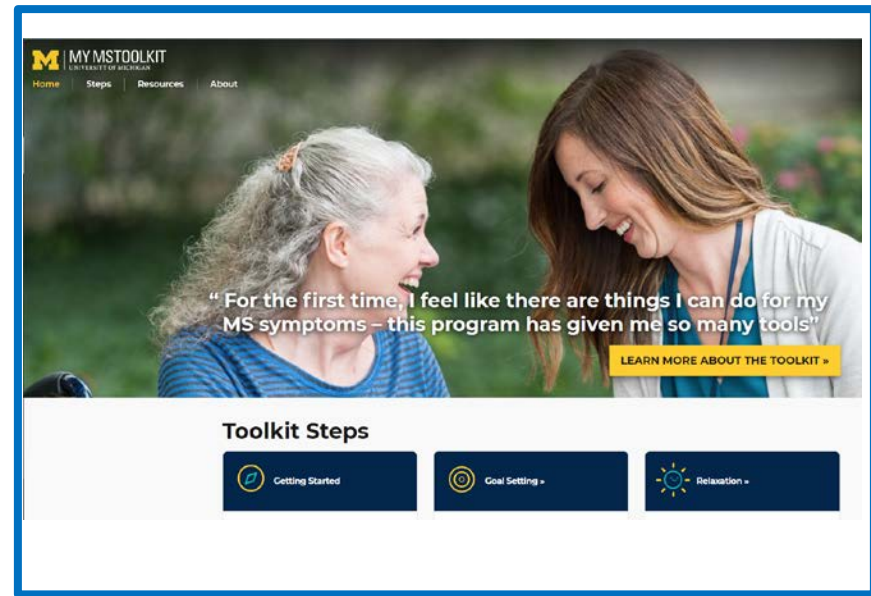
Queens University, Ontario



Building capacity for MS self-management research and knowledge translation

Anna Kratz, PhD

University of Michigan



My MS Toolkit:

<https://mymstoolkit.com/>

**Mentor based fellowship in Rehabilitation Research –
Training to Advance Rehabilitation Research**

Abbey Hughes, MA, PhD

Johns Hopkins University



Reducing depression and anxiety in individuals with MS and their caregivers: An emotion regulation skills training intervention

Dawn Ehde, PhD
University of Washington



**Mindfulness-based cognitive therapy and
cognitive behavioral therapy for chronic pain
in multiple sclerosis**

Summary

- Self-management requires a change in behavior
 - Evidence is strong for addressing fatigue
 - Need to work with a professional to determine the critical elements
- Fatigue is related to your physical, mental and social/emotional activity
- Online programs may offer solutions for depression and anxiety
- Mindfulness based therapy may be one way to address pain in MS

MS Wellness Resources

- **National MS Society MS Navigator**
 - Phone 1-800-344-4867
 - Email ContactUsNMSS@nmss.org
 - Website www.NationalMSSociety.org
- **To find more information on the Society's Wellness research visit:**
<http://www.nationalmssociety.org/Research/Research-We-Fund>

Questions?

kathleen.zackowski@nmss.org



**National
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**Society Resources
We are Here**

Connection Volunteer Website

For Connection Program Volunteers

Peer Connections:
One-on-One

> For Connection
Program Volunteers



SHARE

Like 2

Tweet

Share

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IN THIS ARTICLE

- > Resources for volunteers
- > Recorded All Society Leader Calls
- > MS 101 Webinars
- > Group meeting discussion guides and toolkits

ASK an MS Expert tomorrow December 4

Managing MS as a Team

MS can affect everyone in your circle of support. Partners, spouses, family, and friends can be drawn more closely together by their shared concerns and collaborative efforts.

Join us for a discussion with families affected by MS. Hear how they support each other, tackle decision-making, adjust to new relationship roles, and learn about resources to support your success from a Society MS Navigator.

Spanish ASK an MS Expert December 16

Tema del mes(Topic): Que hay de Nuevo en Investigación en EM/
What's New in Ms Research

Presentadora (Speaker): Dra. Mirla Avila. Neuróloga. Texas Tech.

Para Inscribirse (Registration):

<https://www.nationalmssociety.org/Resources-Support/Library-Education-Programs/Ask-an-MS-Expert-Webinar-Series>

Fecha (Date): Miércoles, 16 de Diciembre del 2020 (12/16/2020)

Hora (Time): 4:00 pm PST; 5:00 pm MST; 6:00 pm CST; 7:00 pm EST

Open Enrollment Reminders

Open enrollment is a critical time for people with MS to learn about their coverage options and to make sure they are enrolled in the plan best suited to their needs and budget for the coming year.

For questions about open enrollment please connect with an MS Navigator at 1-800-344-4867 Monday-Friday (7am-5pm MT) or email us at ContactUsNMSS@nmss.org.

Important Open Enrollment Reminders

The deadlines for Medicare and Marketplace are approaching quickly.

Medicare Part D and Medicare Advantage open enrollment is **October 15 to December 7**

Marketplace enrollment is from **November 1 to December 15**

Café' Con Leche

Conversation and Support in Spanish for People Living with Multiple Sclerosis

The National MS Society wants to make sure that everyone affected by MS can connect with others, feel supported, and receive reliable information regardless of where they are.

Meetings are the 2nd Tuesday of each month at 4:00 p.m. ET. For more information or to register call 1-800-344-4867, option 3, or nationalMSSociety.org/Espanol

Updated Emotional Support Resources



Emotional Support Resources

MS Navigator®

An MS Navigator can be reached at 1-800-344-4867 anytime 7 a.m. - 5 p.m. MT Monday-Friday. Chat is also available on the National MS Society site. MS Navigators are available by email as well at ContactUsNMSS@nmss.org.
<https://www.nationalmssociety.org/MSNavigator>

National MS Society Self-Help Groups

National MS Society self-help groups focus on advocacy, education and empowerment by providing social and emotional support within a peer setting. Individuals come together at to seek and provide support while building a sense of community through the power of connection. <https://www.nationalmssociety.org/Resources-Support/Find-Support/Join-a-Local-Support-Group>

MSFriends® Helpline

The MSFriends helpline connects interested individuals with volunteers living with MS for 1:1 peer connection via phone. MSFriends provides confidential conversations by connecting you directly to volunteers who know first-hand what is it like to live with MS. Volunteers are available 7 days a week from 7 a.m. – 10 p.m. MT.
www.nationalMSSociety.org/MSFriends

MSFriends® Paired

The MSFriends paired program connects interested individuals to trained volunteer via a pairing process based on selected criteria. These connections meet via phone, email or video calls based on a mutually agreed upon availability. Email PeerConnections@nmss.org to learn how to register.

Happy the App

The National MS Society also has a collaboration with Happy the App to ensure that people living with MS get the emotional support they need. Happy the App is a 24/7 phone-based service provided through a mobile phone app that connects individuals experiencing everyday stresses, life struggles or feeling lonely with compassionate listeners.
[Happy the App: National MS Society](#)

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

CONNECTING LEADERS TO LEADERS

- 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

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instagram.com/MSsociety



twitter.com/MSsociety



youtube.com/nationalMSsociety



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