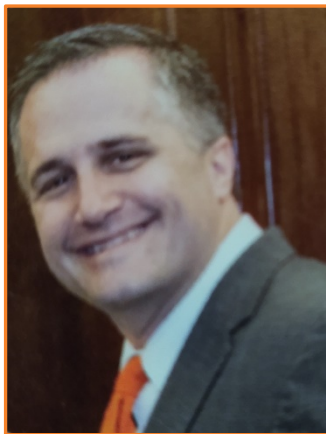




# Support Volunteers Drop-In Call August 20, 2020

Hosted by:



**Tony Bernard**  
Director of Program  
Implementation & 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 "View Who's Talking", a participant count of "1", a chat icon, and a settings gear icon. A participant card for "Wenda Carlson" (WC) is visible. At the bottom, there are four control buttons: "Mic" (muted), "Camera" (off), "Screen" (off), and "Leave".

**Open Chat box** (arrow pointing to the chat icon)

**Camera and Audio settings** (arrow pointing to the settings gear icon)

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** (arrow pointing to the bottom control buttons)

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

- **NEWS:** Going digital through December 31<sup>st</sup>
- We are here to support you! - New support email: [peerconnections@nmss.org](mailto:peerconnections@nmss.org)
- Connection Program Volunteer Website: <https://www.nationalmssociety.org/Resources-Support/Find-Support/Connect-with-Peers-One-on-One/For-Connection-Program-Volunteers>

# ADVOCACY UPDATE



**Karen Mariner**

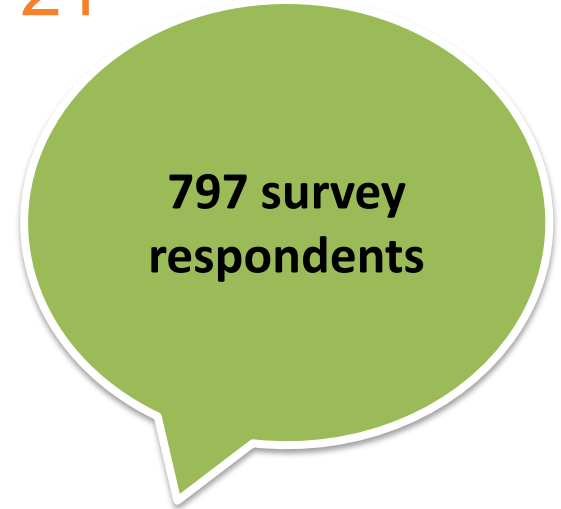
VP, ADVOCACY

# COVID Survey: Purpose

- Understand how the COVID-19 public health crisis impacted people affected by MS
- Identify trends/data to inform Society's response to pandemic
  - Advocacy
  - Services
  - Research

# General Information

- Survey was open from May 1-21
- Survey distribution
  - Society’s “full file” email
  - MS Activist Connector
  - Social Media
- Survey was **NOT** limited to people diagnosed with COVID-19
  - 2% of respondents diagnosed with COVID-19



# COVID-19 Income Impact

*“I have not had any income in months. I have applied for government assistance and contacted all my creditors, mortgage company, utilities to hold off until I can figure it out”*

*“Was let go from my job due to being a high-risk employee”*

*“It has been difficult as I get disability income. We have needed to get additional supplies as I was diagnosed with COVID-19. My credit cards are maxed out”*

24% of respondents reported negative; 46% reported neutral feelings about economy

# What is impacting people the most related to COVID-19 & MS

**Risk exposure to COVID**

**Safety Concerns about returning to community**

**Access to healthcare providers and medications**

# MS Therapies/Medications

**17% altered their use of MS therapy or medications**

Race	Yes	No
White	16%	84%
Black/African-American	18%	82%
Hispanic/Latino	30%	70%

*“My infusion for Ocrevus has been delayed due to risks associated to COVID. I worry about how this will impact my access to treatment and my MS stability long-term”*



# Telehealth

**44% of  
respondents  
accessed  
telehealth  
services**

*“It has been so convenient as transportation is really difficult for someone who doesn’t qualify for government assistance”*

*“Not a fan. This is no substitute for a physical exam and hopefully is not something for which we’re charged a full exam fee”*

*“Wonderful experience. My neurologist is over 100 miles away so this may prove to be a new method for future appointments”*

# What do people need?

*“More up to date information on the effect of COVID-19 on MS patients using DMT’s.”*

*“Not sure. Feel very isolated.”*

*“Guidance on how we should interact as country goes back to work.”*

*“Someone to bathe me...my husband only bathes me once a week.”*



# Key Findings

- 24% had a **negative** feelings and 46% felt **neutral** about their economic security.
- COVID has highlighted the **income inequality** that exists between Whites/Blacks
- Medical, Neighborhood/Physical Environment and Healthcare are impacting people with MS
- 17% **altered the use** of their MS therapy
- 44% have accessed **telehealth services** for MS care

# Informing our Advocacy Work

- **Policy Priorities**
  - Federal Level
    - CARES Act
    - Next CARES package
  - State Level
    - Standards of Care
    - Nursing Homes
    - CARES funding
- **2021 Policy Priorities**
  - Policy Survey

# Get Involved

MS Activist  
Network

District Activist  
Leader

Government  
Relations Advisory  
Committee

Share Your Story

State Action Day



**National  
Multiple Sclerosis  
Society**

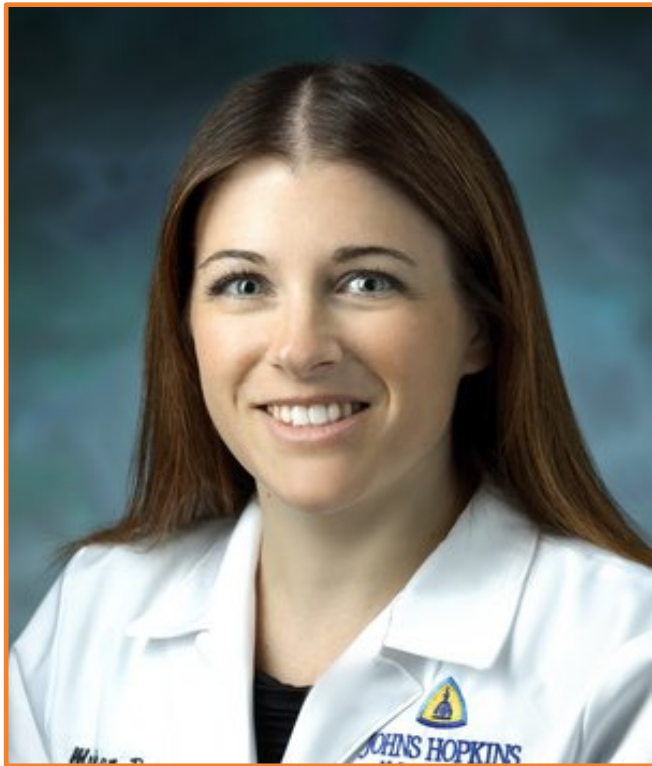
**Society Resources  
We are Here**

# Support for Leaders and Groups

- **We are going digital through December 31<sup>st</sup>**
- **Ongoing Drop In Calls**
  - Thursdays at noon PST/3EST
  - August 27: Peer Support
- **MS Navigator is available to help!**
- **Find Doctors and Resources Online**

# Topic: MS Cognitive Symptoms, Assessment, and Strategies

Friday, August 21<sup>st</sup> 10:00 a.m. PT/1:00 ET



**Meghan L. Beier, M.A., Ph.D.**

Assistant Professor of Physical Medicine  
and Rehabilitation  
Johns Hopkins University School of  
Medicine



# Pregúntale a un Experto en Esclerosis Múltiple



## Esclerosis Múltiple en las Diferentes Etapas de la Vida

**Ingrid Loma-Miller, MD**  
**Neurólogo**

**Centro de Esclerosis Múltiple  
de Tidewater**

# Connection Volunteer Website

## For Connection Program Volunteers

Peer Connections:  
One-on-One

> For Connection  
Program Volunteers



SHARE

Like 2

Tweet

Share

11

### IN THIS ARTICLE

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

# Emotional Support Resources

- [Happy the App](#)
- [Find Doctors and Resources Tool](#)
- [Facebook Group: National MS Society Community](#)
- [MS Navigator is available to help!](#)
- [HelpPRO](#)
  - Online search tool
- [Behavioral Health Treatment Services Locator](#)
  - Nationwide behavioral health services & resources
- [NeedyMeds.org](#)
  - Mental Health clinic locator

# 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](http://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