

# 2020 Policy Priorities

February 18, 2020



**PUBLIC POLICY  
CONFERENCE**

**#MSPPC20**

# Speaker

## **Bari Talente**

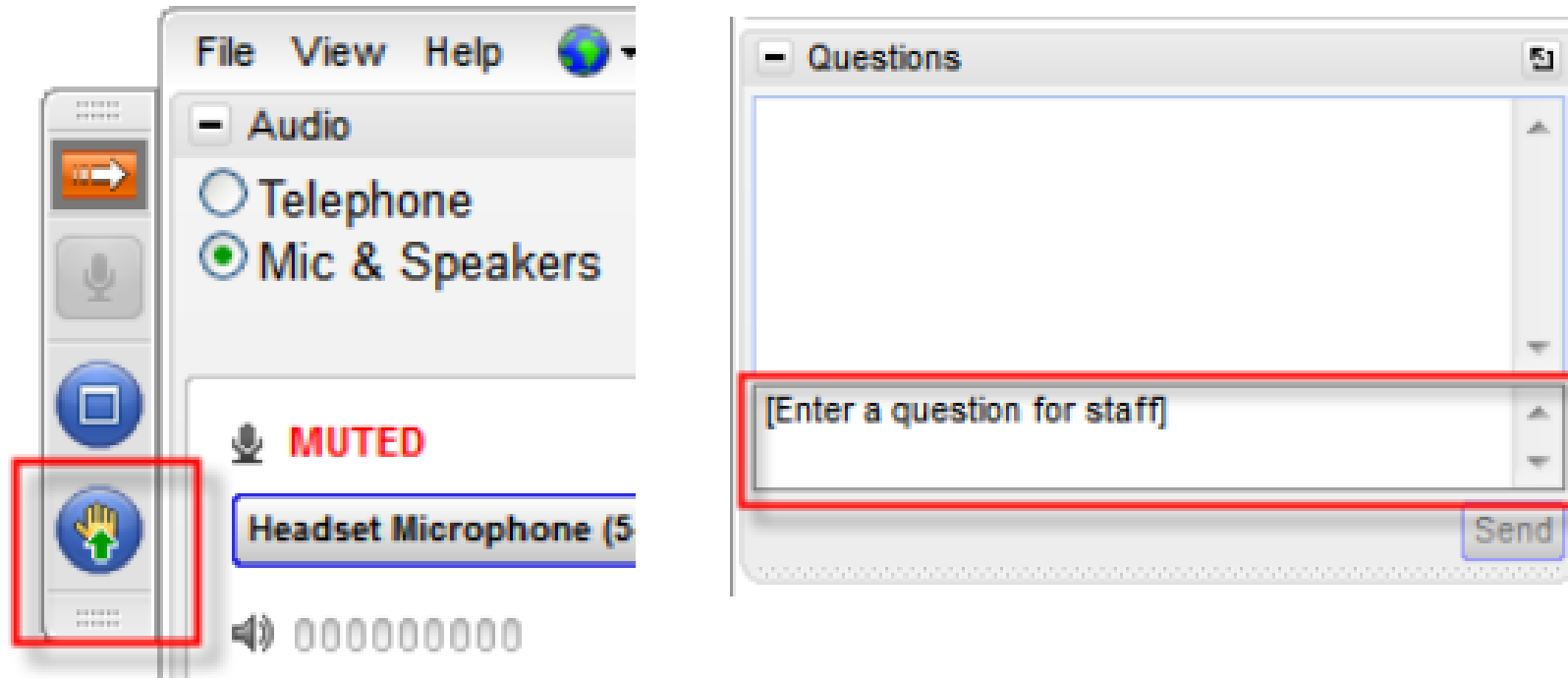
Executive Vice President,  
Advocacy



# Webinar Logistics

- We are using GoToWebinar for this training
- You are currently on mute
- Q&A at the end
  - Use “raise hand” function or question chat box
- Webinar is being recorded and all information will be posted on [www.nationalmssociety.org/ppc](http://www.nationalmssociety.org/ppc)

# Webinar Logistics



# Purpose and Agenda

- **Purpose:** Prepare all MS activists for 2020 policy work
- **Agenda:**
  - Congress 101
  - Policy Priority: End Surprise Billing
  - Policy Priority: Funding MS Policy Priorities
  - Policy Priority: Access to MS Medications
  - Policy Priority: Disaster Management and Relief
  - Questions

## COMPARING THE HOUSE OF REPRESENTATIVES TO THE SENATE

House		Senate
435	Number of Members	100
2 Years	Length of Terms	6 Years
25	Minimum Age for Members	30
Many Rules, More Formal	Organization	Few Rules, Less Formal
By Population	Representation of the States	Equal

# Make-up of the 116<sup>th</sup> Congress

House Partisan Balance	
Party	116th Congress
Democratic	232
Republican	197
Independent	1
Vacancies	5
<b>Total</b>	<b>435</b>

Senate Partisan Balance	
Party	116th Congress
Democratic	45
Republican	<b>53</b>
Independent	2
<b>Total</b>	<b>100</b>

# Speaker

## Grant Couch

Senior Director of Federal  
Government Relations





# Priority: End Surprise Billing

## Why It's Important:

- Surprise bills can be financially burdensome for those living with multiple sclerosis
- No patient should receive a surprise bill from an out-of network provider when seeking care in an in-network facility.
- Living with MS can be challenging enough and surprise bills place an undue burden on those living with a chronic disease.

# Priority: End Surprise Billing

## Request for Congress:

- Pass the bipartisan and bicameral compromise to end surprise billing by May 22nd.
  - This solution was supported by three Congressional Committees of jurisdiction and is supported by the Administration.
  - It is the most comprehensive solution proposed.
  - Would reduce premiums, and
  - Save taxpayers \$24 billion according to the Congressional Budget Office

# Priority: End Surprise Billing

Wow

I was experiencing multiple sclerosis symptoms and went to an in-network hospital but received an out-of-network bill from a provider I never even saw.

How

According to Kaiser Family Foundation, Americans are most concerned about being able to afford surprise bills, even more than health insurance premiums, rent, or mortgage payments. Congress needs to fix this issue.

Now

Pass the bipartisan and bicameral agreement supported by the Senate HELP Committee, House Energy and Commerce Committee, and House Education and Labor Committee.

# Speaker

## **Leslie Ritter**

Associate Vice President,  
Federal Government Relations



# Priority: Federal Funding of MS Research Priorities

- **Federal Government Funding Process**
  - Two-step process:
    1. President's Budget Request
    2. Congressional Process
      - Budget resolution
      - **Appropriations cycle \***
- **House and Senate Appropriations Committees**
  - Subcommittees on Defense and Labor, Health and Human Services and Education

# Priority: Federal Funding of MS Research Priorities

## Why It's Important:

- The Society leverages federal investments to foster novel research and expedite solutions for people with MS.
  - MS Research Program at the Department of Defense (MSRP)
  - National Institutes of Health (NIH)
  - National Neurological Conditions Surveillance System (Surveillance system)

# Priority: Federal Funding of MS Research Priorities

## Request for Congress:

- Support federal investment in MS research for fiscal year 2021 by providing:
  - **\$20 million** for the MSRP
  - **\$44.7 billion** for the NIH
  - **\$5 million** for the Surveillance System

# Priority: Federal Funding of MS Research Priorities

Wow

- My disease modifying therapy is helping to manage my MS, but the disease is still progressing. We must increase research funding to help scientists find a cure.

How

- Innovative treatments and prioritizing a cure for MS will require robust federal investment in all kinds of research.

Now

Provide:

- \$20 million for the MSRP
- \$44.7 billion for the NIH
- \$5 million for the Surveillance System at the CDC



# Speaker

## **Bari Talente**

Executive Vice President,  
Advocacy



# Priority: Access to MS Medications

## Why It's Important:

- **Medications can only change lives if people can affordably access them.**
  - 40% of people with MS alter or stop taking their disease modifying treatment (DMT) due to cost.
  - A recent study showed that MS DMT costs nearly tripled over 7 years
  - More than half of people with MS are very concerned about being able to afford their DMT in the coming years.

# Priority: Access to MS Medications

## Request for Congress:

- Pass legislation to lower high drug prices and out-of-pocket costs.
  - Changes are needed across the prescription drug supply chain.
  - People who rely on high priced medications need changes now, and we can continue to work on additional solutions in the future.

# Priority: Access to MS Medications

Wow

I've been on the same DMT for years, and the price keeps going up. I often need to use a credit card to pay for my medication.

How

Passage of the CREATES Act last year was one small step to improving access; now it's time for Congress to pass additional legislation.

Now

Pass legislation to lower high drug prices and out-of-pocket costs.

# Speaker

**Kim Calder**

Senior Director, Health Policy



# Priority: Disaster Management and Relief

## Why It's Important:

- People with disabilities are two to four times more likely to be critically or fatally injured in a disaster.
- A major lesson of past disasters is that we are better prepared if older adults and people with disabilities are included in planning for the response, recovery and mitigation efforts.
- Delays in accessing needed health care among Medicaid beneficiaries forced to relocate across state lines due to a disaster have resulted in earlier disability and premature death, and health care providers and institutions have had to care for people in need without being paid.

# Priority: Disaster Management and Relief

## Request for Congress:

- Please cosponsor:
  - S. 1755/H.R. 3208- the Real Emergency Access for Aging and Disability Inclusion in Disasters Act (REAADI)
  - S.1754/H.R. 3215-the Disaster Relief Medicaid Act (DRMA)

# Priority: Disaster Management and Relief

Wow

It's terrifying to hear that people with disabilities are two to four times more likely to be critically or fatally injured in a disaster.

How

READI would include a role for individuals with disabilities in disaster preparation and response. DRMA provides continuity of care and access to Medicaid when individuals are evacuated across state lines.

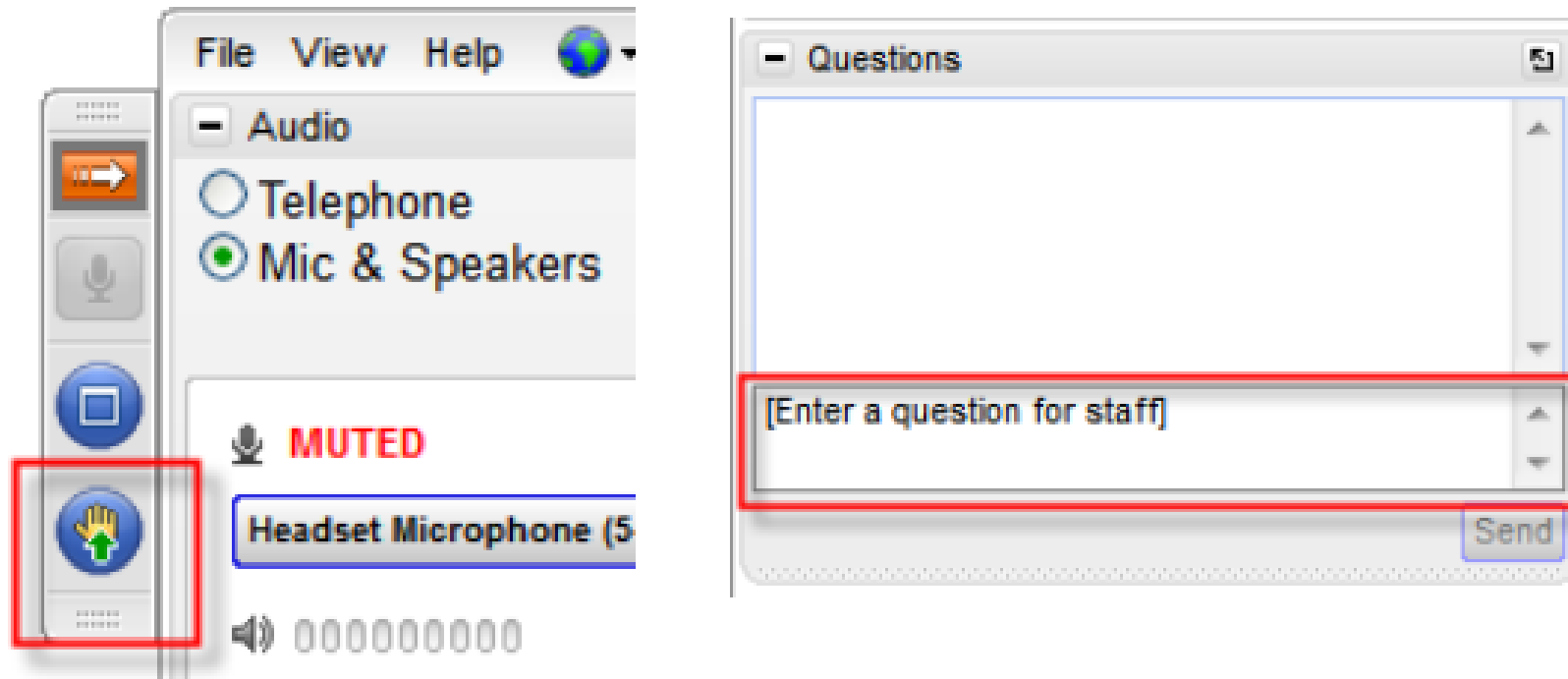
Now

Please cosponsor:

S. 1755/H.R. 3208- the Real Emergency Access for Aging and Disability Inclusion in Disasters Act (READI)  
S.1754/H.R. 3215-the Disaster Relief Medicaid Act (DRMA)



# Questions???



# What's Next?

- Action alert
- Social media
  - @msactivist
- Get to know your elected officials
- Public Policy Conference