



## **National MPS Society LEGISLATIVE MEETING AGENDA**

### **INTRODUCTION (1 minute)**

- Introduce yourself – your name, where you live
- Explicitly state that you are a constituent
- Tell legislator or aide that you are here today as a volunteer for the National MPS Society to talk about MPS or ML diseases and the impact on patients and families

### **EXPLAIN THE MPS SOCIETY'S MISSION (1 minute)**

- Use provided talking points on MPS Society as a basis

### **BRIEFLY EXPLAIN MPS, PROGRESSION, IMPACT ON FAMILIES AND LACK OF TREATMENT (1 minute)**

- Use provided talking points on MPS or ML as a basis

### **SHARE YOUR PERSONAL EXPERIENCE WITH MPS or ML (5 minutes)**

- Use the provided guide to shape your story
- Share a picture of your child and your family
- Share what you think is most important to you and what you think will help the lawmaker understand the depth and breadth of the impact of MPS or ML

### **BRIEFLY DISCUSS THE NATIONAL MPS SOCIETY'S LEGISLATIVE AGENDA (3 MINUTES)**

- Use provided talking points on National MPS Society's Legislative Priorities
- Leave behind the legislative priorities fact sheet

### **RELATIONSHIP BUILDING (5 minutes)**

- Ask some questions of your lawmaker/aide to learn about him/her, what is important to him/her, and how best to communicate:
  - How do you most like to hear from constituents?
  - Are you on Facebook or Twitter and do you communicate with constituents through those forums?

- What are the issues for our state that most concern you?
- Have you interacted with others in our states who are impacted by rare diseases?
- Ask for his/her advice:
  - When is the best time to be in touch with you to talk about our legislative priorities?
  - Do you have any suggestions for what we could or should be doing to advocate for MPS-related issues?
- Ask to continue to build the relationship:
  - May I continue to be in touch with you to keep you informed about MPS and relevant policy issues?
- Offer to serve as a resource:
  - Please be in touch with me if you have any questions about MPS or ML – I may not know the answer but will be happy to connect you with someone who does!

**CONCLUSION (1 minute)**

- Thank legislator or aide for taking the time to meet you with today
- Exchange business cards
- Leave behind the MPS/ML Diseases Fact Sheet and the Legislative Policy Priorities Fact Sheet

For more information, contact: Stephanie Bozarth, Chair, National MPS Society Advocacy Committee at [stephanie.bozarth@mppsociety.org](mailto:stephanie.bozarth@mppsociety.org).