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@mpssociety.org.