



Guide to Sharing Your Personal Experience with MPS and ML

Sharing your personal experience with MPS or ML is a very powerful way to engage legislators and secure their support. In fact, it will be the most important part of your meeting. Your story will make MPS or ML real for legislators in a way that facts and data simply can't. Your personal experience will be the aspect of the meeting that legislators are most likely to remember and discuss with colleagues. The power of your personal story cannot be overstated!

To shape your personal story in a way that best supports the meeting goals, it can help to think through the following questions.

1. **How has MPS or ML affected the life of your loved one?**
2. **How has MPS or ML affected your family?**
 - a. **What are the day-to-day impacts?**
 - b. **How has it impacted you emotionally? Socially? Economically?**
 - c. **What specific examples can you provide that illustrate the depth and breadth of the impacts?**
 - i. **Number of days missed from work or overall impact on your ability to work**
 - ii. **Number of doctor appointments over the course of a month or the number of hours spent in doctor appointments**
 - iii. **Medical costs**
 - iv. **What does your child have to deal with that other children do not? Are there things your child cannot do because of MPS or ML?**
3. **How do you want this legislator to feel? What can you tell them about your experience with MPS that will make them feel this way?**
4. **What do you want this legislator to do? What can you tell them about your experience with MPS that will motivate them to act?**
5. **What challenges do you face that would be helped by the legislative actions you are requesting?**

Also, it is important to:

- **Keep it brief.** Getting the legislator's attention is important, and a story that is too long or unstructured can lose meaning. A story that is 3-5 minutes will allow you to share the most important aspects of your experience with MPS or ML. Less is actually more – give them a glimpse into your life and experience and it will have a BIG impact.

- **Bring a picture.** A picture of your child is important as it gives your lawmaker a visual connection to your story and makes your meeting even more memorable.
- **Don't get bogged down in medical details or too many facts.** The legislator will get all the facts that he or she needs in the information that you leave at the end of the meeting. Tell your story and talk about what your life is like because of MPS or ML. Focus on making the lawmaker FEEL something, not on having them understand all the facts.
- **Remember that you are the expert in this story.** While legislators are experts in what they do, they are not experts in MPS or ML. The information and experience that you have is valuable and will help them better understand MPS or ML and the challenges for individuals and families.

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