

MEETING OUTLINE AND TALKING POINTS FOR YOUR SENATE MEETINGS

BEFORE THE MEETING

Be prompt and patient.

- Be on time and prepared to wait if needed.
- Plan what you want to say and provide essential background information.

DURING THE MEETING

Start with a thank you.

- Thank the Senator or his/her staff for their service to you as their constituent and for taking time to meet with you.

Provide background on Mitochondrial Disease

I am meeting with you today because it's Global Mitochondrial Disease Awareness Week and we need your help. You may not have heard about mitochondrial disease, but it is a very real disease and impacts many.

- Mitochondria in the cells throughout our bodies are responsible for creating more than 90% of the energy needed to sustain life and support organ function. When they malfunction, organs start to fail – people get sick and even die.
- Every 30 minutes a child is born with mitochondrial disease.
- It is a difficult disease to diagnose because it affects every person differently. Children and adults can have seizures, strokes, severe developmental delays; inability to walk, talk, see, digest food and a host of other complications. If three or more organ systems are involved, mitochondrial disease should be suspected.
- We need our breakthrough! Like the enormous impact on mortality that stem cell transplant has had for those suffering blood cancers.....like the life sustaining maintenance medications that have change the course for AIDS patients...mitochondrial disease patients need a breakthrough that leads to treatments that alleviate symptoms and slow down progression and, ultimately, a cure.
- Science has linked mitochondrial dysfunction with major diseases like Alzheimer's, Parkinson's, diabetes, autism, and even the aging process. Imagine if we unlock the secrets to prevention and a mitochondrial disease cure! It would be a game changer for all of human health.
- UMD, whom, I represent, has had an active effort over a number of years to promote greater research and understanding of mitochondrial disease and to help families to access caregivers who can help with diagnosis (which is a huge problem) and treatment.

- **TELL YOUR PERSONAL CONNECTION TO MITOCHONDRIAL DISEASE**

You will want to make this personal and be passionate about how the disease impacts you and/or your family.

- **MAKE THE ASKS**

I would like the Senator to Join Senator Robert Casey of Pennsylvania in Co-Sponsoring “The Medical Nutrition Equity Act or S. 1194.”

- S.1194 is important to me and my family because it would provide for the coverage of medically necessary food and vitamins for digestive and inherited metabolic disorders, like mitochondrial disease, under Federal health programs and private health insurance, and for other purposes.
- Explain why this coverage would be important for you and your family.

If you are meeting with Senator Casey’s Office, you do not need to make this ask but you should tell them that you are here to thank him for introducing this bill and why it is important to you.

MEETING WRAP UP

Thank the member for their service to you as their constituent and for taking time to meet with you. There are no leave behind materials these meetings.

📧 Follow-up.

Make sure to send a thank-you note that reinforces your request of co-sponsorship for S. 1194.