

## MEETING OUTLINE AND TALKING POINTS FOR YOUR CONGRESSIONAL MEETING

### 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 member 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.
- UMDF, 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 to ask the Congressman/Woman to co-sponsor H.R. 5062, which is the “The Advancing Access to Precision Medicine Act. We also have a “Dear Colleague Letter” that we

- This is important to our patient community because it will direct the Department of Health and Human Services to enter into an agreement with the National Academy of Medicine to develop recommendations on how the federal government may reduce barriers to the utilization of genetic and genomic testing.
- Many patients see as many as 20 doctors before they are diagnosed – or if they even receive a diagnosis. Genetic testing would speed up that process and save thousands of dollars in health care costs associated with diagnosis.
- The bill also would let states apply for an exception to the federal medical assistance percentage rate (FMAP) to provide whole genome sequencing clinical services for certain children on Medicaid who have an unresolved disease that is suspected to have a genetic cause

**We are also asking the Congressman to Co-Sponsor H.R. 5115**

This bipartisan legislation was introduced by Congressman Andre Carson (D-IN) and by Congressman Ryan Costello (R-PA) on Rare Disease Day, February 28, 2018 and is known as the RARE ACT.

- H.R. 5115 would bolster and extend funding for the Rare Diseases Clinical Research Network, a NIH-funded initiative comprised of 21 disease research groups conducting interdisciplinary study on rare diseases. The North American Mitochondrial Disease Consortium otherwise known as NAMDC is funded through this and serves our community by gathering information about patients for potential clinical trials and studies.
- H.R. 5115 would task the Centers for Disease Control and Prevention with establishing a nationwide surveillance system to track and record data on rare diseases for research use.
- H.R. 5115 — which also would ramp up federal efforts to alert more health professionals to related diagnoses and treatments. Our disease is very hard to spot, so educating the medical community and providing awareness to the medical community is critical.

**And finally (ONLY IF HE OR SHE IS NOT A CAUCUS MEMBER) are asking that the Congressman/woman join our bi-partisan Congressional Mitochondrial Disease Caucus.**

This Caucus is important to me because it provides information to Members on the challenges our patient community faces and how Congress can be helpful to our patient community.

**IF HE OR SHE IS A MEMBER**

I just want to thank the Congressman/woman for his/her leadership on our issues through his/her membership in the Congressional Mitochondrial Disease Caucus.

**MEETING WRAP UP**

Thank the member for their service to you as their constituent and for taking time to meet with you. Hand out the “Leave Behind’s”

**📧 Follow-up.**

o Make sure to send a thank-you note that reinforces your request and includes any materials that might be useful to the member/staffer based on your meeting.