****

**Congressional Talking Points**

**Introduction**

* Thank you for taking the time to meet with us;
* **[Explain UMDF’s mission]** UMDF promotes research and education for the diagnosis, treatment and cure of mitochondrial disorders and provides support to affected individuals and families.
* **[Explain your personal involvement in the issue of mitochondrial disease – who in your family is afflicted, with what, and what some of the challenges are.]  
    
  Background on Mitochondrial Disease and Dysfunction**
* 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

**Background on UMDF’s Efforts**

* UMDF 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; some of our efforts have included:
* Formation of a Trans-NIH mitochondrial disease working group;
* NIH funding for the North American Mitochondrial Disease Consortium (NAMDC) – a critical shared registry on mito patients;
* The convening of a two-day workshop in 2012 on Translational Research in Mitochondrial Disease as well as a 2014 workshop on the role of dietary supplements and medical foods in the treatment of primary mitochondrial disorders;
* The inclusion in the FISCAL YEAR 15 and FISCAL YEAR 16 Defense Appropriations bill of “mitochondrial disease” as a funded research area under the Defense Peer Reviewed Medical Research Program.
  + But there is still more to do and it remains concerning that in 2012, the NIH estimated that only about $18 million in research funding went toward primary mitochondrial disease when using a broad definition of the term.

**We need your support with the National Institutes of Health (NIH)**

* We understand funding in President Trumps Budget in the fall will be flat – so we need to insure that NIH funding increases
* We would also like it very much if you would join the Congressional Mitochondrial Disease Caucus.  
  Congressman McGovern is our chair --- we are without a republican chair right now. If you are interested in joining, please contact Congressman McGovern’s office.  
    
  **Conclusion/Thank You** We appreciate your time and consideration of these issues and I would like to follow up with you in a week or so if I could.