

## UMDF SENATE MEETING TALKING POINTS

- Hello, my name is \_\_\_\_\_, and I am from (City) . Thank you for meeting with me today.
- I am a member of the United Mitochondrial Disease Foundation. I am here today to tell you about mitochondrial disease and to ask for your support on legislation that is an issue that is both very personal and important for our nation and public health.
- **About Mitochondrial Disease :**
  - Mitochondria take the oxygen from the air that we breathe and the calories from food that we eat and convert it into the energy that allows all of our organs and systems within the body to function. They are the powerhouses that produce the energy that we need to sustain life.
  - If the mitochondria does not function properly it could impact any or all of our organs and systems. The brain may be impaired, vision or hearing may be lost, the heart may be weakened, there may be digestive problems – any system could be affected. The symptoms range from mild to severe for each affected person.
  - The first case of mitochondrial disease was diagnosed in an adult in the 1960s and in the pediatric population in the 1980s. Medical researchers have already determined that 1 in 4000 children will develop a mitochondrial disease by age 10.
  - They are certain that the actual number is much higher. In fact, a recent study in the UK found that 1 in 200 healthy people carry the mutation that could develop into a mitochondrial disease.

### **Further:**

- Researchers have determined that mitochondrial dysfunction is at the core of many common diseases and conditions that affect millions of people, including: Alzheimer's disease, Parkinson's disease, diabetes, ALS, and the Gulf War Syndrome and others. Recent studies have also demonstrated a link to autism.
- A greater understanding of mitochondrial function could lead to treatments for a wide range of conditions and potentially help millions of people, but it is also very personal to me.

- **Briefly tell your own story.**
- We are asking for the leadership of the Senator on this issue.  
We are asking Senator \_\_\_\_\_ to co-sponsor S.2858, the Brittany Wilkinson Mitochondrial Disease Research and Treatment Enhancement Act and be supportive of the measure. I have a copy of the information in this package for your (for the Senator)
- The legislation expands upon existing research efforts and fosters greater coordination among NIH Institutes that have been involved with different aspects of mitochondrial research. To ensure that the necessary coordination occurs, an "Office of Mitochondrial Medicine" is established.
- QUESTIONS