

UMDF HOUSE AND SENATE MEETING TALKING POINTS

- Hello, my name is _____, and I am from (city/state). Thank you for meeting with us today.
- We are members of the United Mitochondrial Disease Foundation. Today, our organization is here on Capitol Hill meeting with members of the House and Senate to tell you about mitochondrial disease and to ask for help from (Congressman/Senator)_____.
- This is an issue that is both very personal and important for our nation and public health.
- **About Mitochondrial Disease :**
 - Mitochondria takes the oxygen from the air that we breath and the calories from food that we eat and converts 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 Congressman/Senator _____:

- Congressman Jim McDermott of Washington has introduced H.R. 3502 . The legislation is called the "Mitochondrial Medicine Research and Treatment Enhancement Act".

(If this is a meeting with your Congressman, say:)

We would like Congressman _____ to Co-sponsor H.R. 3502.

- 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.

(If this meeting is with your Senator say:)

- Congressman Jim McDermott of Washington has introduced H.R. 3502 . The legislation is called the "Mitochondrial Medicine Research and Treatment Enhancement Act".

We would like Senator _____ to consider introducing a companion measure in the Senate or serve as a co-sponsor.

- 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

