How to Engage with Federal Agencies

National Institutes of Health (NIH):

Charles Mohan, Jr.
CEO and Executive Director
The United Mitochondrial Disease Foundation
The View of the NIH
OUR SIMILARITIES ARE GREATER THAN OUR DIFFERENCES
Engaging Individuals and Communities

How to Identify and Partner with the Right Advocacy Group

How Best to Achieve Common Ground? Get on the ground and work your way up!*

How to Identify and Partner with the Right Advocacy Group
Patriotism is not a short and frenzied burst of emotion but the long and steady dedication of a lifetime.”

Thomas Jefferson
A Multi-Systemic Disease needed a Multi-Systemic approach
WE NEED YOU TO CALL THEM!

Specter & Casey

ASK OUR US SENATORS TO SUPPORT THE
BRITTANY WILKINSON MITOCHONDRIAL MEDICINE RESEARCH AND TREATMENT ENHANCEMENT ACT
TO BE INTRODUCED BY SENATOR BARBARA BOXER

Arlen Specter
Pittsburgh Office: 412-644-3400
Washington, D.C. Office: 202-224-4254

Robert P. Casey, Jr.
Pittsburgh Office: 412-803-7370
Washington, D.C. Office: 202-224-6324
Supporting H.R. 3502
Write a letter asking your Congressman to support H.R. 3502.

Thank You Rep. McDermott
Send a letter to thank Rep. Jim McDermott for being our 'Champion' in the House by introducing H.R. 3502

Thank you for your Leadership
Thank your United States Congressman for agreeing to be an original co-sponsor of H.R. 3502
H.R. 3502

To amend the Public Health Service Act to establish an Office of Mitochondrial Medicine at the National Institutes of Health, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

JULY 23, 2009

Mr. McDermott, Mr. Kissell, Mr. Conyers of Michigan, Mr. Waters of California, Mr. Towns of Pennsylvania, Mr. Ellerman; Mr. Burton, Mr. Roe, Mr. Adler of New Jersey, Mr. Melton, Mr. Frankel, Mr. Thompson, Mr. Van Hollen, and Mr. Torricelli of California introduced the following bill, which was referred to the Committee on Energy and Commerce.

A BILL

To amend the Public Health Service Act to establish an Office of Mitochondrial Medicine at the National Institutes of Health, and for other purposes.

1. Title I created by the Senate and House of Representatives of the United States of America in Congress assembled.

2. SECTION 1. SHORT TITLE.

3. This Act may be cited as the "Mitochondrial Medicine Research and Treatment Enhancement Act.".

4. SEC. 2. FINDINGS AND PURPOSE.

(a) FINDINGS.—Congress finds the following:

S. 2858

To amend the Public Health Service Act to establish an Office of Mitochondrial Medicine at the National Institutes of Health, and for other purposes.

IN THE SENATE OF THE UNITED STATES

DEC. 13, 2009

Mr. Boxer, for himself, Mr. Enzi, Mr. Kehr, and Mr. Cappiello introduced the following bill, which was read twice and referred to the Committee on Health, Education, Labor, and Pensions.

A BILL

To amend the Public Health Service Act to establish an Office of Mitochondrial Medicine at the National Institutes of Health, and for other purposes.

1. Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled.

2. SECTION 1. SHORT TITLE.

3. This Act may be cited as the "Brittany Wilkinson Mitochondrial Disease Research and Treatment Enhancement Act.".

4. SEC. 2. FINDINGS AND PURPOSE.

(a) FINDINGS.—Congress finds the following:
Legislation

“Mitochondrial Medicine Research and Treatment Enhancement Act”

H.R. 3502

Introduced by US Congressman James McDermott (D-7th/WA)

S-2858

Introduced by US Senator Barbara Boxer (D-CA)
• NIH & UMDF meeting on May 17, 2011 Presented the UMDF story to 25 Directors, Deputy Directors, Program Officers
• UMDF/NIH Work Session – March 8-9, 2012

Title: Translational Research in Primary Mitochondrial Diseases: Challenges and Opportunities

Goals
1. Share information related to primary mitochondrial disease among the NIH Intramural and Extramural Research Program Investigators
2. Develop and/or enhance systems to facilitate future collaboration and sharing of information
3. Survey obstacles, needs and priorities of primary mitochondrial diseases research
4. Develop mechanisms to enhance translation of basic science discoveries to diagnostics and therapeutics
Senator Barbara Boxer has introduced Senate Resolution 490 (S. Res. 490), which applauds the NIH for this effort and encourages them to follow the recommendations made in the white paper. (Adopted by Senate Dec 2012)

S. Res. 490 also Designates the week of September 16, 2012, as “Mitochondrial Disease Awareness Week”.

Sen. Feinstein D-CA
Sen. Kerry D-MA
Sen. Shaheen D-NH
Sen. Blumenthal D-CT
Sen. Lieberman I-CT
Sen. Menendez D-NJ
Sen. Webb D-VA
“Mitochondria 101 – How Something So Small Is So Important To Human Life.” (September 2012)

“Mitochondria – At the Heart of it all” – a look at many other diseases associated with Mitochondrial Dysfunction. (March, 2013)

“Mitochondria: Potential Treatments and Therapies That Could Benefit Many” (September, 2013)

“NIH/FDA overview of initiatives in mitochondrial research” (April, 2014)

“Causes and Consequences of Damage to Mitochondria on the Warfighter from Gulf War Illness to Traumatic Brain Injury (September, 2014)

Mitochondrial Health: Unlocking the Potential for Disease Prevention” (April, 2015)

“Mitochondrial Dysfunction and its implications for the Cardiac Patient” (October 20, 2015)

“Mitochondria and the Connection with Alzheimer’s Disease” (May 11, 2016)
After mitochondrial disease was included in the Congressionally Directed Medical Research Program, UMDF:

- Recruited more than 30 patients or caregivers to serve as Consumer Reviewers for research proposals.

- Recruited 20 research scientists to serve as research proposal reviewers.

We continue to work to assist CMDRP in the recruitment of both sets of proposal reviewers.
DESTINY IS NOT A MATTER OF CHANCE,
IT IS A CHOICE;
IT IS NOT A THING TO BE WAITED FOR,
IT IS A THING TO BE ACHIEVED

Shaw

AND THE TIME IS NOW!
Coordination
Communication
Collaboration

C C C C C C

CURES
And
Finally........

A Simple Guide to Understanding the political process
Rare Disease Week 2017
On Capitol Hill

Thank you!

Charles A Mohan Jr
UMDF CEO