

112TH CONGRESS
2D SESSION

S. RES. 490

Designating the week of September 16, 2012, as “Mitochondrial Disease Awareness Week”, reaffirming the importance of an enhanced and coordinated research effort on mitochondrial diseases, and commending the National Institutes of Health for its efforts to improve the understanding of mitochondrial diseases.

IN THE SENATE OF THE UNITED STATES

JUNE 12, 2012

Mrs. BOXER (for herself, Mr. MENENDEZ, Mr. LIEBERMAN, Mr. BLUMENTHAL, Mrs. FEINSTEIN, Mrs. SHAHEEN, Mr. WEBB, and Mr. KERRY) submitted the following resolution; which was referred to the Committee on Health, Education, Labor, and Pensions

NOVEMBER 15, 2012

Committee discharged; considered and agreed to

RESOLUTION

Designating the week of September 16, 2012, as “Mitochondrial Disease Awareness Week”, reaffirming the importance of an enhanced and coordinated research effort on mitochondrial diseases, and commending the National Institutes of Health for its efforts to improve the understanding of mitochondrial diseases.

Whereas Brittany Wilkinson, the first Youth Ambassador of the United Mitochondrial Disease Foundation, joined other Youth Ambassadors of the United Mitochondrial

Disease Foundation in working tirelessly to raise awareness about mitochondrial diseases;

Whereas mitochondrial diseases result from a defect that reduces the ability of the mitochondria in a cell to produce energy;

Whereas, as mitochondria fail to produce enough energy, cells cease to function properly and eventually die, leading to the failure of organ systems and possibly the death of the affected individuals;

Whereas mitochondrial diseases can present themselves at any age, and mortality rates vary depending upon the particular disease;

Whereas the most severe mitochondrial diseases result in the progressive loss of function in multiple organs, including the loss of neurological and muscle function, and death within several years;

Whereas mitochondrial diseases are a relatively newly identified group of diseases, first recognized in the late 1960s, and diagnosis of mitochondrial diseases is extremely difficult;

Whereas there are more than 100 identified primary mitochondrial diseases, but researchers believe there are several hundred other types of unidentified mitochondrial diseases and further research is necessary to help identify those diseases;

Whereas mitochondrial dysfunction is associated with many diseases, such as Parkinson's disease, Alzheimer's disease, amyotrophic lateral sclerosis, autism, diabetes, cancer, and many other diseases associated with aging;

Whereas research into primary mitochondrial diseases can provide applications to biomedical research and a window

into our understanding of many other diseases, including possible treatments and cures for diseases such as Parkinson's disease, Alzheimer's disease, amyotrophic lateral sclerosis, autism, diabetes, cancer, and many other diseases associated with aging;

Whereas researchers estimate that one in 4,000 children will develop a mitochondrial disease related to an inherited mutation by 10 years of age, and recent studies of umbilical cord blood samples show that one in 200 people could develop a mitochondrial disease in their lifetime;

Whereas researchers also believe that those numbers could be much higher, given the difficulty associated with diagnosing mitochondrial disease and the many cases that are either misdiagnosed or never diagnosed;

Whereas there are no cures for mitochondrial diseases, nor are there specific treatments for any of those diseases;

Whereas human energy production involves multiple organ systems, and therefore primary mitochondrial diseases research involves many Institutes at the National Institutes of Health;

Whereas, according to the National Institutes of Health, more than \$600,000,000 is being spent on research related to mitochondrial functions, of which \$18,000,000 is being spent on actual primary mitochondrial diseases research;

Whereas the National Institutes of Health has taken an increased interest in primary mitochondrial diseases and has sponsored a number of activities in recent years aimed at advancing mitochondrial medicine, including incorporating research into functional variations in mito-

chondria in the Transformative Research Awards Initiative;

Whereas, in March 2012, the National Institutes of Health convened a 2-day symposium entitled “Translational Research in Primary Mitochondrial Diseases: Obstacles and Opportunities”, which brought together leading government and private sector researchers and drug developers to share information related to primary mitochondrial diseases, develop systems to facilitate future collaboration, survey obstacles, needs, and priorities of primary mitochondrial diseases research, and develop mechanisms to enhance translation of basic science discoveries to diagnostics and therapeutics; and

Whereas, as a consequence of the symposium, a white paper has been developed that identifies current research challenges and impediments and a suggested course of action to address those challenges: Now, therefore, be it

1 *Resolved*, That the Senate—

2 (1) designates the week of September 16, 2012,
3 as “Mitochondrial Disease Awareness Week”;

4 (2) reaffirms the importance of an enhanced
5 and coordinated research effort aimed at improving
6 the understanding of primary mitochondrial diseases
7 and the development of treatments and cures;

8 (3) commends the National Institutes of Health
9 for its efforts to organize the symposium entitled
10 “Translational Research in Primary Mitochondrial
11 Disease: Obstacles and Opportunities” to improve
12 the understanding of mitochondrial diseases and to

1 enhance collaboration and chart a course for the fu-
2 ture with respect to research on mitochondrial dis-
3 eases;

4 (4) encourages the National Institutes of
5 Health to place a greater priority on research into
6 primary mitochondrial diseases, to continue to ex-
7 plore the connections between mitochondrial dys-
8 function and other systemic diseases, and to promote
9 collaboration and coordination among the Institutes
10 of the National Institutes of Health and with other
11 organizations; and

12 (5) encourages the National Institutes of
13 Health to consider the recommendations and address
14 research directions identified in the white paper de-
15 veloped from the symposium described in paragraph
16 (3), including—

17 (A) enhanced emphasis on research regard-
18 ing basic mitochondrial physiology, variations in
19 mitochondrial function in different body tissues,
20 and improvements in the manipulation of
21 mitochondrial DNA;

22 (B) supporting research that will provide
23 the basis for drug development, including im-
24 proved mouse models, efforts to achieve break-
25 throughs in in vivo research capability, con-

1 sensus development around assays, and next
2 generation sequencing;

3 (C) expansion and support of stable, long-
4 term patient registries and biospecimen reposi-
5 tories in collaboration with patient advocacy
6 groups to promote enrollment and ultimately
7 pave the way for natural history trials; and

8 (D) the establishment of a working group
9 to develop a system for the continued inter-
10 action among the Institutes within the National
11 Institutes of Health and with other organiza-
12 tions and the establishment of a website on re-
13 search on primary mitochondrial diseases.

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