

111TH CONGRESS
1ST SESSION

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 31, 2009

Mr. McDERMOTT (for himself, Mr. CONNOLLY of Virginia, Ms. WASSERMAN SCHULTZ, Mr. JOHNSON of Georgia, Mr. TIM MURPHY of Pennsylvania, Mr. ELLSWORTH, Ms. ESHOO, Mr. KIRK, Mr. ADLER of New Jersey, Mr. MCGOVERN, Mr. BOSWELL, Mr. THORNBERRY, Mr. VAN HOLLEN, and Mr. THOMPSON 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 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Mitochondrial Medi-
5 cine Research and Treatment Enhancement Act”.

6 **SEC. 2. FINDINGS AND PURPOSE.**

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

1 (1) Mitochondrial disease results when there is
2 a defect that reduces the ability of the mitochondria
3 in a cell to produce energy. As the mitochondria fail
4 to produce enough energy, the cell will cease to func-
5 tion properly and will eventually die. Organ systems
6 will begin to fail, and the life of the individual is
7 compromised or ended.

8 (2) There are more than 40 specifically identi-
9 fied mitochondrial diseases, but the vast majority
10 have not yet been identified.

11 (3) Mitochondrial diseases are a relatively newly
12 diagnosed group of diseases, first recognized in the
13 late 1960s. Diagnosis is extremely difficult for a
14 number of reasons.

15 (4) Mitochondrial diseases can present them-
16 selves at any age, with associated mortality rates
17 that vary depending upon the particular disease. The
18 most severe diseases result in progressive loss of
19 neurological and liver function, and death within
20 several years.

21 (5) According to the National Institute of Envi-
22 ronmental Health Sciences, half of those affected by
23 mitochondrial disease are children, who show symp-
24 toms before age five and approximately 80 percent
25 of whom will not survive beyond the age of 20.

1 (6) Mitochondrial dysfunction is also associated
2 with numerous other related disorders, including
3 many common neurological diseases (such as Parkin-
4 son's, Alzheimer's, ALS, and autism), and other dis-
5 eases associated with aging, diabetes, cancer, and
6 obesity.

7 (7) Mitochondrial disease is most commonly the
8 result of genetic mutation, either in the nuclear
9 DNA or in the mitochondrial DNA. Some
10 mitochondrial diseases also are attributable to envi-
11 ronmental factors, including prescription medica-
12 tions, that interfere with mitochondrial function.

13 (8) Researchers estimate that one in 4,000 chil-
14 dren will develop a mitochondrial disease related to
15 an inherited mutation by the age of 10 years, and
16 that 1,000–2,000 children are born each year in the
17 United States who will develop mitochondrial disease
18 in their lifetimes. However, studies of umbilical cord
19 blood samples show that one in 200 children are
20 born with both normal and mutant mitochondrial
21 DNA, and the number of children with these
22 mutations who actually develop a disease is un-
23 known.

1 (2) inserting after section 404G the following
2 new section:

3 **“SEC. 404H. OFFICE OF MITOCHONDRIAL MEDICINE.**

4 “(a) ESTABLISHMENT.—There is established within
5 the Office of the Director of NIH an office to be known
6 as the Office of Mitochondrial Medicine (in this section
7 referred to as the ‘Office’), which shall be headed by a
8 Director (in this section referred to as the ‘Director’), ap-
9 pointed by the Director of NIH.

10 “(b) MITOCHONDRIAL MEDICINE RESEARCH
11 PLAN.—

12 “(1) IN GENERAL.—The Director shall develop,
13 make publicly available, and implement a written
14 plan to facilitate research into mitochondrial medi-
15 cine.

16 “(2) CONTENTS.—The plan required under
17 paragraph (1) shall include the following objectives:

18 “(A) Improving coordination of research
19 related to mitochondrial medicine among the
20 national research institutes and between the
21 National Institutes of Health and outside re-
22 searchers.

23 “(B) Providing training to research sci-
24 entists and health professionals engaged in re-
25 search related to mitochondrial medicine.

1 “(C) Providing training to health care pro-
2 viders regarding the diagnosis of mitochondrial
3 disease and dysfunction.

4 “(D) Establishing scientific review groups
5 with expertise in mitochondrial medicine to
6 oversee relevant research projects in the Na-
7 tional Institutes of Health.

8 “(3) CONSULTATION.—In developing the plan
9 under paragraph (1), the Director shall consult
10 with—

11 “(A) the Director of the National Cancer
12 Institute;

13 “(B) the Director of the National Institute
14 of Child Health and Human Development;

15 “(C) the Director of the National Institute
16 of Environmental Health Sciences;

17 “(D) the Director of the National Heart,
18 Lung, and Blood Institute;

19 “(E) the Director of the National Institute
20 of Neurological Disorders and Stroke;

21 “(F) the Director of the National Institute
22 of Diabetes and Digestive and Kidney Diseases;

23 “(G) the Director of the National Eye In-
24 stitute; and

1 “(H) the heads of such other institutes
2 and offices as the Director considers appro-
3 priate.

4 “(4) UPDATES.—The Director shall update the
5 plan required under paragraph (1) on a biennial
6 basis.

7 “(c) RESEARCH GRANTS.—In addition to any grants
8 otherwise awarded by the National Institutes of Health
9 for research in mitochondrial medicine, the Director shall
10 annually award—

11 “(1) at least five grants for integrated, multi-
12 project research programs related to mitochondrial
13 medicine; and

14 “(2) at least five grants for planning activities
15 associated with integrated, multi-project research
16 programs related to mitochondrial medicine.

17 “(d) CENTERS OF EXCELLENCE.—

18 “(1) IN GENERAL.—The Director may award
19 grants to institutions or consortiums of institutions
20 to establish Mitochondrial Medicine Centers of Ex-
21 cellence to promote interdisciplinary research and
22 training related to mitochondrial medicine.

23 “(2) USE OF FUNDS AWARDED.—A grant
24 awarded under paragraph (1) shall be used to—

1 “(A) conduct basic and clinical research re-
2 lated to mitochondrial medicine;

3 “(B) facilitate training programs for re-
4 search scientists and health professionals seek-
5 ing to engage in research related to
6 mitochondrial medicine;

7 “(C) develop and disseminate programs
8 and materials to provide continuing education
9 to health care professionals regarding the rec-
10 ognition, diagnosis, and treatment of
11 mitochondrial disease and dysfunction; and

12 “(D) provide living stipends for research
13 scientists and health professionals enrolled in
14 mitochondrial research training programs.

15 “(e) NATIONAL REGISTRY; BIOREPOSITORY.—

16 “(1) NATIONAL REGISTRY.—The Director shall
17 establish a national registry for the maintenance and
18 sharing for research purposes of medical information
19 collected from patients with mitochondrial disease or
20 dysfunction.

21 “(2) BIOREPOSITORY.—The Director shall es-
22 tablish a national biorepository for the maintenance
23 and sharing for research purposes of tissues and
24 DNA collected from patients with mitochondrial dis-
25 ease or dysfunction.

1 “(f) DEFINITION.—In this section, the term
2 ‘mitochondrial medicine’ means medical treatment related
3 to mitochondrial disease or dysfunction.”.

4 (b) DEVELOPMENT OF MITOCHONDRIAL MEDICINE
5 RESEARCH PLAN.—The Director of the Office of
6 Mitochondrial Medicine shall develop and make publicly
7 available the mitochondrial medicine research plan re-
8 quired under section 404H(b)(1) of the Public Health
9 Service Act, as added by subsection (a) of this section,
10 not later than 180 days after the date of the enactment
11 of this Act.

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