

HOUSE No.

The Commonwealth of Massachusetts

PRESENTED BY:

John W. Scibak

To the Honorable Senate and House of Representatives of the Commonwealth of Massachusetts in General Court assembled:

The undersigned legislators and/or citizens respectfully petition for the passage of the accompanying bill:

An Act providing for care and treatment of patients with mitochondrial disease.

PETITION OF:

NAME: John W. Scibak	DISTRICT/ADDRESS: 2nd Hampshire
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[SIMILAR MATTER FILED IN PREVIOUS SESSION
SEE HOUSE, NO. 1077 OF .]

The Commonwealth of Massachusetts

In the Year Two Thousand and Nine

AN ACT PROVIDING FOR CARE AND TREATMENT OF PATIENTS WITH MITOCHONDRIAL DISEASE.

Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:

1 SECTION 1. Notwithstanding any general or special law to the contrary, the Department of
2 Public Health and the Division of Medical Assistance and all providers of health benefit plans as defined
3 in chapter 176j and chapter 176m of the General Laws, as appearing in the 2004 Official Edition, shall
4 provide coverage and payment for prescribed treatment for mitochondrial disease. Said treatment shall
5 include, but not be limited to, the use of vitamin and nutritional supplements, such as CoEnzyme Q10,
6 Vitamin E, Vitamin C, Vitamin B1, Vitamin B2, Vitamin K1, and L-Carnitine.

7

8 SECTION 2. All patients, regardless of age, will be eligible for treatment coverage for mitochondrial
9 disease if they meet one of the following criteria:

- 10 (a) Documented diagnosis of a mitochondrial disorder through enzyme analysis and/or
11 mitochondrial DNA analysis, and or characteristic features on tissue biopsy;
- 12 (b) Multiple system involvement characteristic for mitochondrial disease and clinical, radiologic or
13 biochemical markers typical for mitochondrial disorders and inconclusive alternative diagnosis
14 testing; or
- 15 (c) Definitive diagnosis of mitochondrial disorder in a first-degree relative AND at least two of the
16 criteria in section 2(b) listed above.

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18 SECTION 3. Any provider of a health benefit plan may require the submission of a letter of medical
19 necessity from a qualified health care professional prior to the approval of any treatment for
20 mitochondrial disease.

21 SECTION 4. The Commissioner of the Department of Public Health shall appoint a Mitochondrial Disease
22 Advisory Committee, hereafter referred to as the committee, to consult with the department in the
23 administration of this act and the provision of services for persons afflicted with mitochondrial disease.
24 The committee shall be composed of five persons, with one representative from the Department of
25 Public Health, one representative from the Division of Medical Assistance, one representative from a
26 private health insurer in the Commonwealth, one physician experienced in mitochondrial disease, one
27 representative from the Mitochondrial Disease Action Committee, and one member from the general
28 public. The commissioner shall appoint one member as chairman. Each member shall hold office for a
29 term of four years and until his successor is appointed and qualified. The committee shall meet as
30 frequently as the chairman deems necessary, but not less than once each year.

31 The committee members shall serve without compensation but shall be reimbursed for actual
32 expenses incurred in carrying out their official duties.

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