

HOUSE No. 1033

The Commonwealth of Massachusetts

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

8 SECTION 2. All patients, regardless of age, will be eligible for treatment coverage for
9 mitochondrial 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,
13 radiologic or biochemical markers typical for mitochondrial disorders and inconclusive
14 alternative diagnosis testing; or

15 (c) Definitive diagnosis of mitochondrial disorder in a first-degree relative AND at least
16 two of the criteria in section 2(b) listed above.

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

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

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