

HOUSE No. 1077

By Mr. Scibak of South Hadley, petition of John W. Scibak and others relative to insurance coverage and payment for prescribed treatment for mitochondrial disease. Financial Services.

The Commonwealth of Massachusetts

PETITION OF:

John W. Scibak
James R. Miceli
Peter V. Kocot

Christine E. Canavan
Jennifer M. Callahan

In the Year Two Thousand and Seven.

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

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

4 (a) Documented diagnosis of a mitochondrial disorder through
5 enzyme analysis and/or mitochondrial DNA analysis, and or charac-
6 teristic features on tissue biopsy;

7 (b) Multiple system involvement characteristic for mitochondrial
8 disease and clinical, radiologic or biochemical markers typical for

9 mitochondrial disorders and inconclusive alternative diagnosis
10 testing; or

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

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

1 SECTION 4. The Commissioner of the Department of Public
2 Health shall appoint a Mitochondrial Disease Advisory Committee,
3 hereafter referred to as the committee, to consult with the depart-
4 ment in the administration of this act and the provision of services
5 for persons afflicted with mitochondrial disease. The committee
6 shall be composed of five persons, with one representative from the
7 Department of Public Health, one representative from the Division
8 of Medical Assistance, one representative from a private health
9 insurer in the Commonwealth, one physician experienced in mito-
10 chondrial disease, one representative from the Mitochondrial Dis-
11 ease Action Committee, and one member from the general public.
12 The commissioner shall appoint one member as chairman. Each
13 member shall hold office for a term of four years and until his suc-
14 cessor is appointed and qualified. The committee shall meet as fre-
15 quently as the chairman deems necessary, but not less than once each
16 year.

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