

HOUSE No. 3261

The Commonwealth of Massachusetts

PRESENTED BY:

David Paul Linsky

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 adoption of the accompanying bill:

An Act relative to the research and treatment of Lyme Disease.

PETITION OF:

NAME:	DISTRICT/ADDRESS:
<i>David Paul Linsky</i>	<i>5th Middlesex</i>
<i>Harriette L. Chandler</i>	
<i>Carolyn C. Dykema</i>	<i>8th Middlesex</i>
<i>Peter V. Kocot</i>	<i>1st Hampshire</i>
<i>Cory Atkins</i>	<i>14th Middlesex</i>
<i>Timothy R. Madden</i>	<i>Barnstable, Dukes and Nantucket</i>
<i>Stephen Kulik</i>	<i>1st Franklin</i>
<i>Chris Walsh</i>	<i>6th Middlesex</i>
<i>William N. Brownsberger</i>	
<i>Thomas P. Conroy</i>	<i>13th Middlesex</i>
<i>Daniel B. Winslow</i>	<i>9th Norfolk</i>
<i>James J. Dwyer</i>	<i>30th Middlesex</i>
<i>Jennifer E. Benson</i>	<i>37th Middlesex</i>
<i>Tom Sannicandro</i>	<i>7th Middlesex</i>
<i>Michael J. Rodrigues</i>	
<i>Sarah K. Peake</i>	<i>4th Barnstable</i>
<i>Christine E. Canavan</i>	<i>10th Plymouth</i>
<i>Denise C. Garlick</i>	<i>13th Norfolk</i>

Cleon H. Turner

1st Barnstable

Angelo J. Puppolo, Jr.

12th Hampden

HOUSE No. 3261

By Mr. Linsky of Natick, a petition (accompanied by bill, House, No. 3261) of David Paul Linsky and others relative to the research and treatment of Lyme Disease. Public Health.

The Commonwealth of Massachusetts

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In the Year Two Thousand Eleven
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An Act relative to the research and treatment of Lyme 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 or regulation to the contrary, a
2 special commission hereafter referred to as the commission, is hereby established for the purpose
3 of investigating and studying the incidence and impacts in the Commonwealth of Lyme disease
4 and other tick-borne diseases, including but not limited to anaplasmosis, ehrlichiosis, and
5 babesiosis.

6 Said study shall include, but not be limited to, a cost-benefit analysis of: (i) conducting a
7 Lyme disease public health clinical screening study in high risk regions; (ii) developing
8 education materials and training resources for detecting signs and symptoms of tick-borne
9 illnesses in school-aged populations, to be used by clinical providers and school health personnel
10 (iii) statewide surveillance and testing for tick-borne diseases in ticks, and (iv) educating the
11 medical community about research on all aspects of Lyme, both acute and chronic. The
12 commission shall also investigate the availability of grants and federal funds for the study of

13 Lyme disease and other tick-borne diseases to determine if future action is feasible and
14 warranted to support Lyme and tick-borne diseases research in the Commonwealth.

15 Said commission shall consist of: 3 members of the Senate, 1 of whom shall be
16 appointed by the senate minority leader; 3 members of the House of Representatives, 1 of whom
17 shall be appointed by the house minority leader; the commissioner of the Department of Public
18 Health or a designee; the commissioner of the division of health care finance and policy or a
19 designee the director of the state laboratory institute or a designee; the state epidemiologist or a
20 designee; and 4 members to be appointed by the governor, 1 of whom shall be a physician
21 specialized in infectious disease, 1 of whom shall be a professional member of the International
22 Lyme and Associated Diseases Society, and 2 members who shall be considered experts in the
23 treatment or research of Lyme disease. Additionally, there shall be 4 public members, two of
24 whom shall be patients or family members of patients; and two shall be members of Lyme and
25 other tick-borne diseases organizations. One patient shall be appointed by the Senate, one
26 patient by the House of Representatives and the two members of Lyme & other tick-borne
27 diseases organizations shall be appointed by the governor.

28 Said commission shall report to the Senate and House of Representative the results of its
29 investigation and study, together with drafts of legislation, if any, necessary to carry its
30 recommendations into effect, by filing the same with the clerks of the Senate and House of
31 Representatives, who shall forward the same to the joint committee on Public Health and the
32 House and Senate committees on Ways and Means by May 1, 2012.

33 SECTION 2. Chapter 29 of the General Laws is hereby amended by inserting after
34 section 2ZZZ the following section:-

35 Section 2AAAA. (a) There is hereby established and set up on the books of the
36 Commonwealth a separate fund known as the Lyme Disease Research Institute Trust Fund. The
37 University of Massachusetts shall hold the fund in an account or accounts separate from other
38 funds or accounts. Amounts credited to the fund shall be used by the president of the University
39 of Massachusetts or his designee to provide funding grants to the University of Massachusetts
40 Medical School at Worcester for Lyme disease research. Amounts credited to the fund shall not
41 be subject to further appropriation.

42 (b) The president of the University of Massachusetts shall, no later than July 1, annually
43 report to the House and Senate committees on Ways and Means and the joint committee on
44 Public Health. The report shall include: (1) the amounts of non - state funding leveraged as a
45 result of the grants, including in-kind and other non-cash contributions; (2) an annual statement
46 of cash inflows and outflows detailing the sources and uses of funds; and (3) a detailed
47 breakdown of the purposes and amounts of administrative costs charged to the fund.

48 SECTION 3. Chapter 75 of the General Laws is hereby amended by inserting after
49 section 15A the following section:-

50 Section 15B. (a) There is hereby established the Lyme disease research institute, which
51 shall be operated under the direction of the University of Massachusetts Medical School at
52 Worcester and based at the Worcester campus. The institute shall be responsible for conducting
53 research for the Commonwealth on matters related to Lyme disease including the following: (1)
54 the establishment of epidemiological research objectives to determine the long term course of
55 illness for Lyme disease; (2) determination of the effectiveness of different treatment modalities
56 by establishing treatment outcome objectives; (3) the development of sensitive and more

57 accurate diagnostic tools and tests, including a direct detection test for Lyme disease capable of
58 distinguishing active infection from past infection; (4) improving the efficient utilization of
59 diagnostic testing currently available to account for the multiple clinical manifestations of both
60 acute and chronic Lyme disease; (5) providing for the timely evaluation of promising emerging
61 diagnostic methods; and (6) the sponsoring of scientific conferences on Lyme disease ,
62 including reporting and consideration of the full spectrum of clinically based knowledge, with
63 the first of such conferences to be held not later than 24 months after the date of enactment of
64 this section.

65 (b) The institute shall maintain the confidentiality of any individual whose personal
66 information is made available to the institute but compliance with individual confidentiality shall
67 not prevent the publication of aggregated research information or case studies wherein personal
68 identifiers have been removed.