

**HOUSE . . . . . No. 03261**

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 passage 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>First Worcester</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>24th Middlesex</i>
<i>Thomas P. Conroy</i>	<i>13th Middlesex</i>
<i>Daniel 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>First Bristol and Plymouth</i>
<i>Sarah K. Peake</i>	<i>4th Barnstable</i>
<i>Christine E. Canavan</i>	<i>10th Plymouth</i>

*Denise Garlick*

*13th Norfolk*

*Cleon H. Turner*

*1st Barnstable*

*Angelo J. Puppolo, Jr.*

*12th Hampden*

# HOUSE . . . . . No. 03261

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

## The Commonwealth of Massachusetts

In the Year Two Thousand Eleven

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 special  
2 commission hereafter referred to as the commission, is hereby established for the purpose of  
3 investigating and studying the incidence and impacts in the Commonwealth of Lyme disease and  
4 other tick-borne diseases, including but not limited to anaplasmosis, ehrlichiosis, and babesiosis.  
5 Said study shall include, but not be limited to, a cost-benefit analysis of: (i) conducting a Lyme  
6 disease public health clinical screening study in high risk regions; (ii) developing education  
7 materials and training resources for detecting signs and symptoms of tick-borne illnesses in  
8 school-aged populations, to be used by clinical providers and school health personnel (iii)  
9 statewide surveillance and testing for tick-borne diseases in ticks, and (iv) educating the medical  
10 community about research on all aspects of Lyme, both acute and chronic. The commission shall  
11 also investigate the availability of grants and federal funds for the study of Lyme disease and

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

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

27

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 section 2ZZZ  
34 the following section:-

35 Section 2AAAA. (a) There is hereby established and set up on the books of the Commonwealth  
36 a separate fund known as the Lyme Disease Research Institute Trust Fund. The University of  
37 Massachusetts shall hold the fund in an account or accounts separate from other funds or  
38 accounts. Amounts credited to the fund shall be used by the president of the University of  
39 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 report  
43 to the House and Senate committees on Ways and Means and the joint committee on Public  
44 Health. The report shall include: (1) the amounts of non - state funding leveraged as a result of  
45 the grants, including in-kind and other non-cash contributions; (2) an annual statement of cash  
46 inflows and outflows detailing the sources and uses of funds; and (3) a detailed breakdown of the  
47 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 section 15A  
49 the following section:-

50 Section 15B. (a) There is hereby established the Lyme disease research institute, which shall be  
51 operated under the direction of the University of Massachusetts Medical School at Worcester and  
52 based at the Worcester campus. The institute shall be responsible for conducting research for the  
53 Commonwealth on matters related to Lyme disease including the following: (1) the  
54 establishment of epidemiological research objectives to determine the long term course of illness

55 for Lyme disease; (2) determination of the effectiveness of different treatment modalities by  
56 establishing treatment outcome objectives; (3 ) the development of sensitive and more accurate  
57 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 information  
66 is made available to the institute but compliance with individual confidentiality shall not prevent  
67 the publication of aggregated research information or case studies wherein personal identifiers  
68 have been removed.