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 passage of the accompanying:

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

PETITION OF:

NAME:	DISTRICT/ADDRESS:
David Paul Linsky	5th Middlesex
Harriette L. Chandler	
	\Box [District]
Carolyn C. Dykema	8th Middlesex
Peter V. Kocot	1st Hampshire
Cory Atkins	14th Middlesex
Timothy R. Madden	Barnstable, Dukes and Nantucket
Stephen Kulik	1st Franklin
Chris Walsh	6th Middlesex
William N. Brownsberger	
	\Box [District]
Thomas P. Conroy	13th Middlesex
Daniel B. Winslow	9th Norfolk
James J. Dwyer	30th Middlesex
Jennifer E. Benson	37th Middlesex
Tom Sannicandro	7th Middlesex

Michael J. Rodrigues	
	\Box [District]
Sarah K. Peake	4th Barnstable
Christine E. Canavan	10th Plymouth
Denise C. Garlick	13th Norfolk
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

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:

SECTION 1. Notwithstanding any general or special law or regulation to the contrary, a special commission hereafter referred to as the commission, is hereby established for the purpose of investigating and studying the incidence and impacts in the Commonwealth of Lyme disease and other tick-borne diseases, including but not limited to anaplasmosis, ehrlichiosis, and babesiosis.

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

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

- patient by the House of Representatives and the two members of Lyme & other tick-borne diseases organizations shall be appointed by the governor.
- 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:-
- 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.
- SECTION 3. Chapter 75 of the General Laws is hereby amended by inserting after
- 49 section 15A the following section:-
- 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 this section.
- (b) The institute shall maintain the confidentiality of any individual whose personal
 information is made available to the institute but compliance with individual confidentiality shall
 not prevent the publication of aggregated research information or case studies wherein personal
 identifiers have been removed.