HOUSE No. 00349

The Commonwealth of Massachusetts

PRESENTED BY:

Jennifer E. Benson

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 establishing a public health Lyme disease research institute at the University of Massachusetts Medical School at Worcester .

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PETITION OF:

NAME:	DISTRICT/ADDRESS:
Jennifer E. Benson	37th Middlesex
Carolyn C. Dykema	8th Middlesex
William N. Brownsberger	24th Middlesex
Ellen Story	3rd Hampshire
James B. Eldridge	Middlesex and Worcester
Jennifer L. Flanagan	Worcester and Middlesex
Susan C. Fargo	Third Middlesex
Jeffrey Sánchez	15th Suffolk

HOUSE No. 00349

By Ms. Jennifer E. Benson of Lunenburg, petition (accompanied by bill, House, No. 00349) of Carolyn C. Dykema and others relative to establishing a public health Lyme disease research institute at the University of Massachusetts Medical School. Joint Committee on Higher Education.

[SIMILAR MATTER FILED IN PREVIOUS SESSION SEE O HOUSE , NO. 4471 OF 2009-2010.]

The Commonwealth of Massachusetts

In the Year Two Thousand Eleven

An Act establishing a public health Lyme disease research institute at the University of Massachusetts Medical School at Worcester .

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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. It is hereby declared that the commonwealth is faced with a serious public health threat of exposure to tick-borne illnesses, specifically Lyme disease. According to the Centers for Disease Control and Prevention, from 1992 to 2006, the incidence of Lyme disease was highest among children 5 to 14 years of age. The persistence of symptomatology in many patients with Lyme disease without reliable testing makes treatment of patients more difficult. If an individual with Lyme disease does not receive treatment, such individual can develop severe heart, neurological, eye, and joint problems. The long-term public health consequences of Lyme

disease jeopardizes the well being of a significant number of residents of the commonwealth. 8 Private funding alone of Lyme disease research cannot address the proliferation of this tick-9 borne illness. Without public funding for research of Lyme disease, the public health of the 10 commonwealth is at risk. By creating a publicly funded institute of research at the University of 11 Massachusetts Medical School at Worcester, the expenditure of public monies thereto constitutes 12 13 serving a valid public health purpose and the enactment of provisions hereinafter set forth is in the public interest and is hereby so declared to be such as a matter of determination by the 14 general court. 15

16 SECTION 2. Chapter 29 of the General Laws is hereby amended by inserting after section17 2ZZZ the following section:-

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

(b) The president of the University of Massachusetts shall, no later than July 1, annually report to
the house and senate committees on ways and means and the joint committee on public health.
The report shall include: (1) the amounts of non-state funding leveraged as a result of the grants,
including in-kind and other non-cash contributions; (2) an annual statement of cash inflows and

outflows detailing the sources and uses of funds; and (3) a detailed breakdown of the purposesand amounts of administrative costs charged to the fund.

31 SECTION 3. Chapter 75 of the General Laws is hereby amended by inserting after section 15A32 the following section:-

Section 15B. (a) There is hereby established the Lyme disease research institute, which shall be 33 operated under the direction of the University of Massachusetts Medical School at Worcester and 34 based at the Worcester campus. The institute shall be responsible for conducting research for the 35 36 commonwealth on matters related to Lyme disease including the following: (1) the establishment of epidemiological research objectives to determine the long term course of illness for Lyme 37 disease; (2) determination of the effectiveness of different treatment modalities by establishing 38 39 treatment outcome objectives; (3) the development of sensitive and more accurate diagnostic tools and tests, including a direct detection test for Lyme disease capable of distinguishing active 40 infection from past infection; (4) improving the efficient utilization of diagnostic testing 41 currently available to account for the multiple clinical manifestations of both acute and chronic 42 Lyme disease; (5) providing for the timely evaluation of promising emerging diagnostic 43 methods; and (6) the sponsoring of scientific conferences on Lyme disease, including reporting 44 and consideration of the full spectrum of clinically based knowledge, with the first of such 45 conferences to be held not later than 24 months after the date of enactment of this section. 46

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