HOUSE No. 349

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 adoption of the accompanying bill:

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

PETITION OF:

NAME:	DISTRICT/ADDRESS:	DATE ADDED:
Jennifer E. Benson	37th Middlesex	2/4/2011
Carolyn C. Dykema	8th Middlesex	2/4/2011
William N. Brownsberger		1/24/2011
Ellen Story	3rd Hampshire	2/3/2011
James B. Eldridge		2/3/2011
Jennifer L. Flanagan		2/3/2011
Susan C. Fargo		2/4/2011
Jeffrey Sánchez	15th Suffolk	2/1/2011

HOUSE No. 349

By Ms. Benson of Lunenburg, a petition (accompanied by bill, House, No. 349) of Jennifer E. Benson and others relative to establishing a public health Lyme disease research institute at the University of Massachusetts Medical School. Higher Education.

[SIMILAR MATTER FILED IN PREVIOUS SESSION SEE 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.

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. 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

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3 Centers for Disease Control and Prevention, from 1992 to 2006, the incidence of Lyme disease

4 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

6 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.

9 Private funding alone of Lyme disease research cannot address the proliferation of this tick-

borne illness. Without public funding for research of Lyme disease, the public health of the

commonwealth is at risk. By creating a publicly funded institute of research at the University of Massachusetts Medical School at Worcester, the expenditure of public monies thereto constitutes 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 general court.

SECTION 2. Chapter 29 of the General Laws is hereby amended by inserting after section 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 purposes and amounts of administrative costs charged to the fund.
- 31 SECTION 3. Chapter 75 of the General Laws is hereby amended by inserting after 32 section 15A the following section:-

Section 15B. (a) There is hereby established the Lyme disease research institute, which shall be operated under the direction of the University of Massachusetts Medical School at Worcester and based at the Worcester campus. The institute shall be responsible for conducting research for the 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 disease; (2) determination of the effectiveness of different treatment modalities by establishing 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 infection from past infection; (4) improving the efficient utilization of diagnostic testing currently available to account for the multiple clinical manifestations of both acute and chronic Lyme disease; (5) providing for the timely evaluation of promising emerging diagnostic methods; and (6) the sponsoring of scientific conferences on Lyme disease, including reporting and consideration of the full spectrum of clinically based knowledge, with 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.