

HOUSE . . . . . No. 4471

The Commonwealth of Massachusetts

PRESENTED BY:

Jennifer 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 .

PETITION OF:

NAME:	DISTRICT/ADDRESS:
Jennifer Benson	37th Middlesex
Ellen Story	3rd Hampshire
David P. Linsky	5th Middlesex
Ann-Margaret Ferrante	5th Essex
Matthew C. Patrick	3rd Barnstable
Carl M. Sciortino, Jr.	34th Middlesex
James Cantwell	4th Plymouth
Todd M. Smola	1st Hampden
Stephen R. Canessa	12th Bristol
Cory Atkins	14th Middlesex
Robert P. Spellane	13th Worcester
Cleon H. Turner	1st Barnstable
Michael J. Rodrigues	8th Bristol
Theodore C. Speliotis	13th Essex
James Arciero	2nd Middlesex
Sean Garballey	23rd Middlesex
Jennifer L. Flanagan	Worcester and Middlesex
James J. O'Day	14th Worcester District

Sarah K. Peake	4th Barnstable
Frank I. Smizik	15th Norfolk
Mary E. Grant	6th Essex
Kate Hogan	3rd Middlesex
Robert S. Hargraves	1st Middlesex

# The Commonwealth of Massachusetts

In the Year Two Thousand and Nine

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  
2 threat of exposure to tick-borne illnesses, specifically Lyme disease. According to the Centers for  
3 Disease Control and Prevention, from 1992 to 2006, the incidence of Lyme disease was highest among  
4 children 5 to 14 years of age. The persistence of symptomatology in many patients with Lyme disease  
5 without reliable testing makes treatment of patients more difficult. If an individual with Lyme disease  
6 does not receive treatment, such individual can develop severe heart, neurological, eye, and joint  
7 problems. The long-term public health consequences of Lyme disease jeopardizes the well being of a  
8 significant number of residents of the commonwealth. Private funding alone of Lyme disease research  
9 cannot address the proliferation of this tick-borne illness. Without public funding for research of Lyme  
10 disease, the public health of the commonwealth is at risk. By creating a publicly funded institute of  
11 research at the University of Massachusetts Medical School at Worcester, the expenditure of public  
12 monies thereto constitutes serving a valid public health purpose and the enactment of provisions  
13 hereinafter set forth is in the public interest and is hereby so declared to be such as a matter of  
14 determination by the general court.

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

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

23 (b) The president of the University of Massachusetts shall, no later than July 1, annually report to the  
24 house and senate committees on ways and means and the joint committee on public health. The report  
25 shall include: (1) the amounts of non-state funding leveraged as a result of the grants, including in-kind  
26 and other non-cash contributions; (2) an annual statement of cash inflows and outflows detailing the  
27 sources and uses of funds; and (3) a detailed breakdown of the purposes and amounts of administrative  
28 costs charged to the fund.

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

31 Section 15B. (a) There is hereby established the Lyme disease research institute, which shall be operated  
32 under the direction of the University of Massachusetts Medical School at Worcester and based at the  
33 Worcester campus. The institute shall be responsible for conducting research for the commonwealth on  
34 matters related to Lyme disease including the following: (1) the establishment of epidemiological  
35 research objectives to determine the long term course of illness for Lyme disease; (2) determination of the  
36 effectiveness of different treatment modalities by establishing treatment outcome objectives; (3) the  
37 development of sensitive and more accurate diagnostic tools and tests, including a direct detection test for  
38 Lyme disease capable of distinguishing active infection from past infection; (4) improving the efficient

39 utilization of diagnostic testing currently available to account for the multiple clinical manifestations of  
40 both acute and chronic Lyme disease; (5) providing for the timely evaluation of promising emerging  
41 diagnostic methods; and (6) the sponsoring of scientific conferences on Lyme disease, including reporting  
42 and consideration of the full spectrum of clinically based knowledge, with the first of such conferences to  
43 be held not later than 24 months after the date of enactment of this section.

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