

HOUSE No. 4471

The Commonwealth of Massachusetts

In the Year Two Thousand 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
2 health threat of exposure to tick-borne illnesses, specifically Lyme disease. According to the
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
5 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
7 heart, neurological, eye, and joint problems. The long-term public health consequences of Lyme
8 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-
10 borne illness. Without public funding for research of Lyme disease, the public health of the
11 commonwealth is at risk. By creating a publicly funded institute of research at the University of
12 Massachusetts Medical School at Worcester, the expenditure of public monies thereto constitutes
13 serving a valid public health purpose and the enactment of provisions hereinafter set forth is in

14 the public interest and is hereby so declared to be such as a matter of determination by the
15 general court.

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

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

25 (b) The president of the University of Massachusetts shall, no later than July 1, annually
26 report to the house and senate committees on ways and means and the joint committee on public
27 health. The report shall include: (1) the amounts of non-state funding leveraged as a result of the
28 grants, including in-kind and other non-cash contributions; (2) an annual statement of cash
29 inflows and outflows detailing the sources and uses of funds; and (3) a detailed breakdown of the
30 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:-

33 Section 15B. (a) There is hereby established the Lyme disease research institute, which
34 shall be operated under the direction of the University of Massachusetts Medical School at
35 Worcester and based at the Worcester campus. The institute shall be responsible for conducting

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

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