

HOUSE No.

The Commonwealth of Massachusetts

PRESENTED BY:

Gloria L. Fox

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 to establish a lupus erythematosus study and registry.

PETITION OF:

NAME:

Gloria L. Fox

DISTRICT/ADDRESS:

7th Suffolk

[SIMILAR MATTER FILED IN PREVIOUS SESSION
SEE HOUSE, NO. 2096 OF 2007-2008.]

The Commonwealth of Massachusetts

—————
In the Year Two Thousand and Nine
—————

AN ACT TO ESTABLISH A LUPUS ERYTHEMATOSUS STUDY AND REGISTRY.

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.

2
3 Chapter 111 of the Massachusetts General Laws is hereby amended by inserting after section 25A, as appearing in
4 the 2000 Official Edition, the following new paragraphs:—

5 The department shall, subject to appropriation, establish a Systemic Lupus Erythematosus (Lupus) registry, by areas
6 and regions of the commonwealth, with specific data to be obtained from urban, low and median income
7 communities, and minority communities of the commonwealth. The department shall have the authority to require
8 physicians, hospitals, laboratories, and other facilities that diagnose such conditions to report cases of Lupus to the
9 department, and to require the submission of such other information pertaining to or in connection with the reported
10 cases as the department deems necessary or appropriate for the purposes of this section. To the extent the
11 department deems possible, the registry shall

12 be compatible with other national models so as to facilitate the coordination of information with other databases.

13 The department shall, subject to appropriation, maintain comprehensive records of all reports submitted pursuant to
14 this section. Such reports shall be confidential in accordance with section 70 and shall be released by the department
15 only upon written request of the patient, his guardian, executor, attorney, or other person designated in writing by
16 said patient. Such reports and records or information contained therein, may also be released by the department to
17 persons authorized by the commissioner to conduct research studies or to other persons, but no such studies shall
18 identify the subjects of said reports or records. Based upon the information provided by the registry, the department
19 shall provide and disseminate Lupus related information which shall included, but not be limited to, geographic
20 patterns or trends in the incidence of each illness in the commonwealth, screening and testing methods, preventive
21 measures, and an analysis of the possible effects of environmental factors.

22 The registry shall provide and disseminate such information through means including but not limited to establishing
23 a toll-free telephone information line, providing written materials to hospitals and health care facilities and
24 publishing on the Internet.

25 Nothing in this section shall be construed to compel any individual to submit to a medical or departmental
26 examination or supervision. The department shall promulgate rules and regulations as are necessary to implement
27 for the administration of this section.