

HOUSE No. 1954

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 adoption of the accompanying bill:

An Act to establish a lupus erythematosus study and registry.

PETITION OF:

NAME:	DISTRICT/ADDRESS:	DATE ADDED:
<i>Gloria L. Fox</i>	<i>7th Suffolk</i>	<i>1/18/2013</i>
<i>Cheryl A. Coakley-Rivera</i>	<i>10th Hampden</i>	
<i>Linda Dorcena Forry</i>	<i>12th Suffolk</i>	
<i>Cory Atkins</i>	<i>14th Middlesex</i>	
<i>Tricia Farley-Bouvier</i>	<i>3rd Berkshire</i>	
<i>Martin J. Walsh</i>	<i>13th Suffolk</i>	<i>1/28/2013</i>
<i>Christine E. Canavan</i>	<i>10th Plymouth</i>	
<i>Kay Khan</i>	<i>11th Middlesex</i>	

HOUSE No. 1954

By Ms. Fox of Boston, a petition (accompanied by bill, House, No. 1954) of Gloria L. Fox and others that the Department of Public Health be directed to establish a Systemic Lupus Erythematosus registry. Public Health.

[SIMILAR MATTER FILED IN PREVIOUS SESSION
SEE HOUSE, NO. 1481 OF 2011-2012.]

The Commonwealth of Massachusetts

In the Year Two Thousand Thirteen

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

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

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

14 The department shall, subject to appropriation, maintain comprehensive records of all
15 reports submitted pursuant to this section. Such reports shall be confidential in accordance with
16 section 70 and shall be released by the department only upon written request of the patient, his

guardian, executor, attorney, or other person designated in writing by said patient. Such reports and records or information contained therein, may also be released by the department to persons authorized by the commissioner to conduct research studies or to other persons, but no such studies shall identify the subjects of said reports or records. Based upon the information provided by the registry, the department shall provide and disseminate Lupus related information which shall included, but not be limited to, geographic patterns or trends in the incidence of each illness in the commonwealth, screening and testing methods, preventive measures, and an analysis of the possible effects of environmental factors.

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

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