

HOUSE No. 4255

The Commonwealth of Massachusetts

HOUSE OF REPRESENTATIVES, July 12, 2012.

The committee on Health Care Financing, to whom was referred the Bill to establish a lupus erythematosus study and registry (House, No. 1481), reports recommending that the same ought to pass with an amendment substituting therefor the accompanying bill (House, No. 4255).

For the committee,

STEVEN M. WALSH.

The Commonwealth of Massachusetts

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In the Year Two Thousand Twelve
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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. Section 25A of chapter 111 of the Massachusetts General Laws, as appearing in
2 the 2010 Official Edition, is hereby amended by adding at the end the following new
3 paragraphs:—

4 The department shall, subject to appropriation, establish a systemic lupus erythematosus registry,
5 by areas and regions of the commonwealth, with specific data to be obtained from urban, low
6 and median income communities, and minority communities of the commonwealth. The
7 department may require physicians, hospitals, laboratories, and other facilities that diagnose such
8 conditions to report cases of lupus to the department, and to require the submission of such other
9 information pertaining to the reported cases as the department deems necessary or appropriate
10 for the purposes of this section. To the extent the department deems possible, the registry shall
11 be compatible with other national models in order to facilitate the coordination of information
12 with other databases.

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

24 The registry shall provide and disseminate such information through means including but not
25 limited to establishing a toll-free telephone information line, providing written materials to
26 hospitals and health care facilities and making information available on a website.

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

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