

HOUSE No. 4096

The Commonwealth of Massachusetts

HOUSE OF REPRESENTATIVES, May 21, 2014.

The committee on Health Care Financing to whom was referred the Bill to establish a lupus erythematosus study and registry (House, No. 1954), reports recommending that the accompanying bill ought to pass with an amendment substituting the accompanying bill (House, No. 4096).

For the committee,

JENNIFER E. BENSON.

The Commonwealth of Massachusetts

In the Year Two Thousand Fourteen

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. Chapter 111 of the Massachusetts General Laws is hereby amended by
2 inserting after section 25A the following section:—

3 Section 25A ½. The department shall, subject to appropriation, establish a Systemic
4 Lupus Erythematosus (Lupus) registry, by areas and regions of the commonwealth, with specific
5 data to be obtained from urban, low and median income communities, and minority communities
6 of the commonwealth. The department shall have the authority to require physicians, hospitals,
7 laboratories, and other facilities that diagnose such conditions to report cases of Lupus to the
8 department, and to require the submission of such other information pertaining to or in
9 connection with the reported cases as the department deems necessary or appropriate for the
10 purposes of this section. To the extent the department deems possible, the registry shall be
11 compatible with other national models so as to facilitate the coordination of information with
12 other databases.

13 The department shall, subject to appropriation, maintain comprehensive records of all
14 reports submitted pursuant to this section. Such reports shall be confidential and shall not be a
15 public record under chapter 66 and shall be released by the department only upon written request
16 of the patient, his guardian, executor, attorney, or other person designated in writing by said
17 patient. Such reports and records or information contained therein, may also be released by the
18 department to persons authorized by the commissioner to conduct research studies or to other
19 persons, but no such studies shall identify the subjects of said reports or records. Based upon the
20 information provided by the registry, the department shall provide and disseminate Lupus related
21 information which shall included, but not be limited to, geographic patterns or trends in the
22 incidence of each illness in the commonwealth, screening and testing methods, preventive
23 measures, and an analysis of the possible effects of environmental factors.

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

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