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HOUSE . . . . . No. 2050

The Commonwealth of Massachusetts

In the Year Two Thousand 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:

SECTION 1.

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

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

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

The department shall, subject to appropriation, maintain comprehensive records of all reports submitted pursuant to this section. Such reports shall be confidential in accordance with 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.