HB6682

LRB095 20881 RPM 51369 b

95TH GENERAL ASSEMBLY

State of Illinois

2007 and 2008

HB6682

by Rep. Tom Cross - Barbara Flynn Currie

SYNOPSIS AS INTRODUCED:

20 ILCS 2310/2310-635 new

Amends the Department of Public Health Powers and Duties Law of the Civil Administrative Code of Illinois. Requires the Department of Public Health to develop and implement a neonatal diabetes mellitus registry pilot program. Requires the Department to create an electronic registry to track glycosylated hemoglobin levels of persons. Requires physicians and other healthcare providers treating a patient with diabetes mellitus with onset before 12 months of age to report the occurrence of all such cases to the Department. Requires clinical laboratories performing glycosylated hemoglobin tests for patients with diabetes mellitus with onset before 12 months of age to report the results of each test that the laboratory performs to the Department. Provides that the Department shall allow access of the registry to neonatal diabetes mellitus research institutions. Provides that these provisions are repealed on December 31, 2011. Contains confidentiality provisions. Effective immediately.

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A BILL FOR

AN ACT concerning State government, which may be referred to as Lilly's Law.

Be it enacted by the People of the State of Illinois, represented in the General Assembly:

Section 5. The Department of Public Health Powers and Duties Law of the Civil Administrative Code of Illinois is amended by adding Section 2310-635 as follows:

(20 ILCS 2310/2310-635 new)

Sec. 2310-635. Neonatal Diabetes Mellitus Registry Pilot Program.

(a) In this Section, "neonatal diabetes mellitus research institution" means an Illinois academic medical research institution that (i) conducts research in the area of diabetes mellitus with onset before 12 months of age and (ii) is functioning in this capacity as of the effective date of this amendatory Act of the 95th General Assembly.

(b) The Department, subject to appropriation or other funds made available for this purpose, shall develop and implement a 3-year pilot program to create and maintain a diabetes mellitus registry. The Department shall create an electronic registry to track the glycosylated hemoglobin level of each person who has a laboratory test to determine that level performed by a physician or healthcare provider or at a clinical laboratory in

this State.

The goals of the registry are as follows:

(1) to help identify new and existing patients with neonatal diabetes;

(2) to provide a clearinghouse of information for individuals, their families, and doctors about these syndromes;

(3) to keep track of patients with these mutations who are being treated with sulfonylurea drugs and their treatment outcomes; and

(4) to help identify new genes responsible for diabetes.

(c) Physicians and other healthcare providers treating a patient in this State with diabetes mellitus with onset before 12 months of age shall report to the Department the following information from all such cases: the name of the physician, the name of the patient, the birthdate of the patient, the patient's age at the onset of diabetes, the patient's birth weight, the patient's blood sugar level at the onset of diabetes, any family history of diabetes of any type, and any other pertinent medical history of the patient. Clinical laboratories performing glycosylated hemoglobin tests in this State as of the effective date of this amendatory Act of the 95th General Assembly for patients with diabetes mellitus with onset before 12 months of age must report the results of each test that the laboratory performs to the Department. The

physician, healthcare provider, or laboratory shall obtain the informed consent of the patient to the disclosure of the patient's information.

(d) The Department shall allow access of the registry to neonatal diabetes mellitus research institutions participating in the pilot program. The Department and the participating neonatal diabetes mellitus research institution shall do the following:

(1) compile results submitted under subsection (c) of this Section in order to track:

(A) the prevalence and incidence of diabetes mellitus among people tested in this State;

(B) the level of control the patients in each demographic group exert over the diabetes mellitus;

(C) the trends of new diagnoses of diabetes mellitus in this State; and

(D) the health care costs associated with diabetes mellitus; and

(2) promote discussion and public information programs regarding diabetes mellitus.

(e) Reports, records, and information obtained under this Section are confidential, privileged, not subject to disclosure, and not subject to subpoena and may not otherwise be released or made public except as provided by this Section. The reports, records, and information obtained under this Section are for the confidential use of the Department and the

participating neonatal diabetes mellitus research institutions and the persons or public or private entities that the Department determine are necessary to carry out the intent of this Section. Medical or epidemiological information may be released as follows:

(1) for statistical purposes in a manner that prevents identification of individuals, health care facilities, clinical laboratories, or health care practitioners;

(2) with the consent of each person identified in the information; or

(3) to promote diabetes mellitus research, including release of information to other diabetes registries and appropriate State and federal agencies, under rules adopted by the Department to ensure confidentiality as required by State and federal laws.

(f) An employee of this State or a participating neonatal diabetes mellitus research institution may not testify in a civil, criminal, special, or other proceeding as to the existence or contents of records, reports, or information concerning an individual whose medical records have been used in submitting data required under this Section unless the individual consents in advance.

(g) Not later than December 1, 2011, the Department shall submit a report to the General Assembly regarding the pilot program that includes the following:

(1) an evaluation of the effectiveness of the pilot

program; and

(2) a recommendation to continue, expand, or eliminate the pilot program.

(h) The Department shall adopt rules to implement the pilot program, including rules to govern the format and method of collecting glycosylated hemoglobin data, in accordance with the Illinois Administrative Procedure Act.

(i) This Section is repealed on December 31, 2011.

Section 99. Effective date. This Act takes effect upon becoming law.