



96TH GENERAL ASSEMBLY

State of Illinois

2009 and 2010

HB0203

Introduced 1/14/2009, by Rep. Tom Cross - Barbara Flynn Currie

SYNOPSIS AS INTRODUCED:

20 ILCS 2310/2310-640 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 Provides that these provisions are repealed on December 31, 2012. Contains confidentiality provisions. Effective immediately.

LRB096 03574 RPM 13599 b

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

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

5 Section 5. The Department of Public Health Powers and
6 Duties Law of the Civil Administrative Code of Illinois is
7 amended by adding Section 2310-640 as follows:

8 (20 ILCS 2310/2310-640 new)

9 Sec. 2310-640. Neonatal Diabetes Mellitus Registry Pilot
10 Program.

11 (a) In this Section, "neonatal diabetes mellitus research
12 institution" means an Illinois academic medical research
13 institution that (i) conducts research in the area of diabetes
14 mellitus with onset before 12 months of age and (ii) is
15 functioning in this capacity as of the effective date of this
16 amendatory Act of the 96th General Assembly.

17 (b) The Department, subject to appropriation or other funds
18 made available for this purpose, shall develop and implement a
19 3-year pilot program to create and maintain a diabetes mellitus
20 registry. The Department shall create an electronic registry to
21 track the glycosylated hemoglobin level of each person who has
22 a laboratory test to determine that level performed by a
23 physician or healthcare provider or at a clinical laboratory in

1 this State.

2 The goals of the registry are as follows:

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

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

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

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

13 (c) Physicians and other healthcare providers treating a
14 patient in this State with diabetes mellitus with onset before
15 12 months of age shall report to the Department the following
16 information from all such cases: the name of the physician, the
17 name of the patient, the birthdate of the patient, the
18 patient's age at the onset of diabetes, the patient's birth
19 weight, the patient's blood sugar level at the onset of
20 diabetes, any family history of diabetes of any type, and any
21 other pertinent medical history of the patient. Clinical
22 laboratories performing glycosylated hemoglobin tests in this
23 State as of the effective date of this amendatory Act of the
24 96th General Assembly for patients with diabetes mellitus with
25 onset before 12 months of age must report the results of each
26 test that the laboratory performs to the Department. The

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

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

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

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

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

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

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

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

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

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

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

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

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

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

23 (g) Not later than December 1, 2012, the Department shall
24 submit a report to the General Assembly regarding the pilot
25 program that includes the following:

26 (1) an evaluation of the effectiveness of the pilot

1 program; and

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

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

8 (i) This Section is repealed on December 31, 2012.

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