

By: Crownover

H.B. No. 740

A BILL TO BE ENTITLED

AN ACT

relating to newborn screening for congenital heart defects.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF TEXAS:

SECTION 1. Section 33.001, Health and Safety Code, is amended by amending Subdivision (1) and adding Subdivision (1-a) to read as follows:

(1) "Congenital heart defect" means an abnormality in the structure and function of the heart that exists at birth.

(1-a) "Heritable disease" means an inherited disease that may result in mental or physical retardation or death.

SECTION 2. Section 33.011, Health and Safety Code, is amended by amending Subsections (a-1) and (c) and adding Subsection (d) to read as follows:

(a-1) Except as provided by this subsection and to the extent funding is available for the screening, the department shall require newborn screening tests to screen for disorders listed as core and secondary conditions in the December 2011 Recommended Uniform Screening Panel of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children [~~core panel and in the secondary targets of the uniform newborn screening panel recommended in the 2005 report by the American College of Medical Genetics entitled "Newborn Screening: Toward a Uniform Screening Panel and System"~~] or other recommendation [~~another report~~] determined by the department to provide more stringent newborn

1 screening guidelines to protect the health and welfare of this
2 state's newborns. The department, with the advice of the Newborn
3 Screening Advisory Committee, may require additional newborn
4 screening tests under this subsection to screen for other disorders
5 or conditions. The department may exclude from the newborn
6 screening tests required under this subsection screenings for
7 galactose epimerase and galactokinase.

8 (c) Except as provided by Subsection (d), the [The]
9 screening tests required by this section must be performed by the
10 laboratory established by the department or by a laboratory
11 approved by the department under Section 33.016.

12 (d) The department may authorize a screening test,
13 including a screening for congenital heart defects, to be performed
14 at a health care facility that provides newborn infant care and that
15 complies with the test procedures and the standards of accuracy and
16 precision required by the department for each screening test.

17 SECTION 3. Sections 33.0111(a), (b), and (f), Health and
18 Safety Code, are amended to read as follows:

19 (a) The department shall develop a disclosure statement
20 that clearly discloses to the parent, managing conservator, or
21 guardian of a newborn child subjected to screening tests under
22 Section 33.011:

23 (1) that the department, any health care facility
24 authorized to perform the tests, or a laboratory established or
25 approved by the department under Section 33.016 may retain for use
26 by the department, health care facility, or laboratory genetic
27 material used to conduct the newborn screening tests and discloses

1 how the material is managed and used subject to this section and
2 Sections 33.0112 and 33.018 [~~33.017~~]; [~~and~~]

3 (2) that reports, records, and information obtained by
4 the department under this chapter that do not identify a child or
5 the family of a child will not be released for public health
6 research purposes under Section 33.018(c-1) [~~33.017(c-1)~~] unless a
7 parent, managing conservator, or guardian of the child consents to
8 disclosure; and

9 (3) that newborn screening blood spots and associated
10 data are confidential under law and may only be used as described by
11 Section 33.018 [~~33.017~~].

12 (b) The disclosure statement required by Subsection (a)
13 must be included on the form developed by the department to inform
14 parents about newborn screening. The disclosure statement must:

15 (1) be in a format that allows a parent, managing
16 conservator, or guardian of a newborn child to consent to
17 disclosure under Section 33.018(c-1) [~~33.017(c-1)~~];

18 (2) include instructions on how to complete the
19 portions of the form described by Subdivision (1);

20 (3) include the department's mailing address; and

21 (4) describe how a parent, managing conservator, or
22 guardian of a newborn child may obtain information regarding
23 consent through alternative sources.

24 (f) This section does not supersede the requirements
25 imposed by Section 33.018 [~~33.017~~].

26 SECTION 4. Section 33.014(a), Health and Safety Code, is
27 amended to read as follows:

1 (a) If, because of an analysis of a specimen submitted under
2 Section 33.011, the department reasonably suspects that a newborn
3 child may have phenylketonuria, another heritable disease,
4 hypothyroidism, or another disorder for which the screening tests
5 are required, the department shall notify the person who submits
6 the specimen that the results are abnormal and provide the test
7 results to that person. The department may notify one or more of
8 the following that the results of the analysis or of a screening
9 test reported to the department under Section 33.015 are abnormal
10 and recommend further testing when necessary:

11 (1) the physician attending the newborn child or the
12 physician's designee;

13 (2) the person attending the delivery of the newborn
14 child that was not attended by a physician;

15 (3) the parents of the newborn child;

16 (4) the health authority of the jurisdiction in which
17 the newborn child was born or in which the child resides, if known;
18 or

19 (5) physicians who are cooperating pediatric
20 specialists for the program.

21 SECTION 5. Section 33.017(c), Health and Safety Code, is
22 amended to read as follows:

23 (c) The advisory committee shall advise the department
24 regarding strategic planning, policy, rules, and services related
25 to newborn screening and additional newborn screening tests for
26 each disorder included in the list described by Section
27 33.011(a-1).

1 SECTION 6. Section 33.0111(g), Health and Safety Code, is
2 repealed.

3 SECTION 7. As soon as practicable after the effective date
4 of this Act, the Department of State Health Services shall
5 implement the changes in law made by this Act to the newborn
6 screening program under Chapter 33, Health and Safety Code.

7 SECTION 8. This Act takes effect September 1, 2013.