

AN ACT

relating to newborn screening for critical congenital heart disease and other disorders.

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

SECTION 1. This Act shall be known as the Taryn Kennedy, Nash Sievers, and Rex Van de Putte Act.

SECTION 2. Section 33.001, Health and Safety Code, is amended by amending Subdivision (1) and adding Subdivisions (1-a) and (1-b) to read as follows:

(1) "Birthing facility" means an inpatient or ambulatory health care facility that offers obstetrical or newborn care services. The term includes:

(A) a hospital licensed under Chapter 241 that offers obstetrical services;

(B) a birthing center licensed under Chapter 244;

(C) a children's hospital; or

(D) a facility that provides obstetrical services and is maintained and operated by this state or an agency of this state.

(1-a) "Critical congenital heart disease" means an abnormality in the structure or function of the heart that exists at birth, causes severe, life-threatening symptoms, and requires medical intervention within the first few hours, days, or months of life.

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

3 SECTION 3. Section 33.011, Health and Safety Code, is
4 amended by amending Subsections (a), (a-1), and (c) and adding
5 Subsections (d), (e), and (f) to read as follows:

6 (a) The physician attending a newborn child or the person
7 attending the delivery of a newborn child that is not attended by a
8 physician shall cause the child to be subjected [~~subject the child~~]
9 to screening tests approved by the department for phenylketonuria,
10 other heritable diseases, hypothyroidism, and other disorders for
11 which screening is required by the department.

12 (a-1) Except as provided by this subsection and to the
13 extent funding is available for the screening, the department shall
14 require newborn screening tests to screen for disorders listed as
15 core and secondary conditions in the December 2011 Recommended
16 Uniform Screening Panel of the Secretary's Advisory Committee on
17 Heritable Disorders in Newborns and Children [~~core panel and in the~~
18 ~~secondary targets of the uniform newborn screening panel~~
19 ~~recommended in the 2005 report by the American College of Medical~~
20 ~~Genetics entitled "Newborn Screening: Toward a Uniform Screening~~
21 ~~Panel and System"~~] or another report determined by the department
22 to provide more stringent newborn screening guidelines to protect
23 the health and welfare of this state's newborns. The department,
24 with the advice of the Newborn Screening Advisory Committee, may
25 require additional newborn screening tests under this subsection to
26 screen for other disorders or conditions. The department may
27 exclude from the newborn screening tests required under this

1 subsection screenings for galactose epimerase and galactokinase.

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

6 (d) The department, with the advice of the Newborn Screening
7 Advisory Committee, shall authorize a screening test for critical
8 congenital heart disease to be performed at a birthing facility
9 that provides care to newborn patients and that complies with the
10 test procedures and the standards of accuracy and precision
11 required by the department for each screening test.

12 (e) If the department under Subsection (d) authorizes the
13 performance at a birthing facility of a screening test for critical
14 congenital heart disease, a birthing facility must perform the
15 screening test on each newborn who is a patient of the facility
16 before the newborn is discharged from the facility unless:

17 (1) the parent declines the screening;

18 (2) the newborn is transferred to another facility
19 before the screening test is performed;

20 (3) the screening test has previously been completed;

21 or

22 (4) the newborn is discharged from the birthing
23 facility not more than 10 hours after birth and a referral for the
24 newborn was made to another birthing facility, physician, or health
25 care provider.

26 (f) Before requiring any additional screening test for
27 critical congenital heart disease, the department must review the

1 necessity of the additional screening test, including an assessment
2 of the test implementation costs to the department, birthing
3 facilities, and other health care providers.

4 SECTION 4. Section 33.0111, Health and Safety Code, is
5 amended by amending Subsections (a), (b), and (f) and adding
6 Subsection (h) to read as follows:

7 (a) The department shall develop a disclosure statement
8 that clearly discloses to the parent, managing conservator, or
9 guardian of a newborn child subjected to screening tests under
10 Section 33.011:

11 (1) that the department or a laboratory established or
12 approved by the department under Section 33.016 may retain for use
13 by the department or laboratory genetic material used to conduct
14 the newborn screening tests and discloses how the material is
15 managed and used subject to this section and Sections 33.0112 and
16 33.018 [~~33.017~~]; [~~and~~]

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

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

26 (b) The disclosure statement required by Subsection (a)
27 must be included on the form developed by the department to inform

1 parents about newborn screening. The disclosure statement must:

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

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

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

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

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

13 (h) Nothing in this section prohibits a physician attending
14 a newborn child from delegating the physician's responsibilities
15 under this section to any qualified and properly trained person
16 acting under the physician's supervision.

17 SECTION 5. Section 33.015(a), Health and Safety Code, is
18 amended to read as follows:

19 (a) Each physician, health authority, birthing facility, or
20 other individual who has the information of a confirmed case of a
21 disorder for which a screening test is required that has been
22 detected by a mechanism other than identification through a
23 screening of a specimen by the department's diagnostic laboratory
24 shall report the confirmed case to the department.

25 SECTION 6. Sections 33.017(b) and (c), Health and Safety
26 Code, are amended to read as follows:

27 (b) The advisory committee consists of members appointed by

1 the commissioner of state health services. The advisory committee
2 must include the following members:

3 (1) at least four physicians licensed to practice
4 medicine in this state, including at least two physicians
5 specializing in neonatal-perinatal medicine [~~health-care~~
6 ~~providers~~];

7 (2) at least two [~~a~~] hospital representatives
8 [~~representative~~];

9 (3) at least two persons who have family members
10 affected by a condition for which newborn screening is or may be
11 required under this subchapter; and

12 (4) at least two health care providers [~~persons~~] who
13 are involved in the delivery of newborn screening services,
14 follow-up, or treatment in this state.

15 (c) The advisory committee shall:

16 (1) advise the department regarding strategic
17 planning, policy, rules, and services related to newborn screening
18 and additional newborn screening tests for each disorder included
19 in the list described by Section 33.011(a-1); and

20 (2) review the necessity of requiring additional
21 screening tests, including an assessment of the test implementation
22 costs to the department, birthing facilities, and other health care
23 providers.

24 SECTION 7. Section 33.0111(g), Health and Safety Code, is
25 repealed.

26 SECTION 8. As soon as practicable after the effective date
27 of this Act, the Department of State Health Services shall

1 implement the changes in law made by this Act to the newborn
2 screening program under Chapter 33, Health and Safety Code.

3 SECTION 9. (a) The change in law made by this Act in
4 amending Section 33.017, Health and Safety Code, regarding the
5 qualifications of members of the Newborn Screening Advisory
6 Committee does not affect the entitlement of a member serving on the
7 committee immediately before the effective date of this Act to
8 continue to serve as a member of the committee for the remainder of
9 the member's term. The change in law applies only to a member
10 appointed on or after the effective date of this Act.

11 (b) As soon as practicable after the effective date of this
12 Act, the commissioner of state health services shall appoint the
13 additional committee members required by Section 33.017, Health and
14 Safety Code, as amended by this Act.

15 SECTION 10. This Act takes effect September 1, 2013.

President of the Senate

Speaker of the House

I certify that H.B. No. 740 was passed by the House on April 24, 2013, by the following vote: Yeas 141, Nays 2, 1 present, not voting; and that the House concurred in Senate amendments to H.B. No. 740 on May 15, 2013, by the following vote: Yeas 143, Nays 1, 2 present, not voting.

Chief Clerk of the House

I certify that H.B. No. 740 was passed by the Senate, with amendments, on May 13, 2013, by the following vote: Yeas 31, Nays 0.

Secretary of the Senate

APPROVED: _____

Date

Governor