

By: Villalba

H.B. No. 1937

A BILL TO BE ENTITLED

AN ACT

relating to newborn screening tests for adrenoleukodystrophy.

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

SECTION 1. The heading to Chapter 33, Health and Safety Code, is amended to read as follows:

CHAPTER 33. ADRENOLEUKODYSTROPHY, PHENYLKETONURIA, OTHER HERITABLE DISEASES, HYPOTHYROIDISM, AND CERTAIN OTHER DISORDERS

SECTION 2. Section 33.001, Health and Safety Code, is amended to read as follows:

Sec. 33.001. DEFINITIONS. In this chapter:

(1) "Adrenoleukodystrophy" means an inherited condition that results in an abnormality in the structure or function of the brain and causes severe, life-threatening symptoms.

(2) "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.

(3) [~~(1-a)~~] "Critical congenital heart disease" means

1 an abnormality in the structure or function of the heart that exists
2 at birth, causes severe, life-threatening symptoms, and requires
3 medical intervention within the first few hours, days, or months of
4 life.

5 (4) [~~(1-b)~~] "Heritable disease" means an inherited
6 disease that may result in intellectual [~~mental~~] or physical
7 disability [~~retardation~~] or death.

8 (5) [~~(2)~~] "Hypothyroidism" means a condition that may
9 cause severe intellectual disability [~~mental retardation~~] if not
10 treated.

11 (6) [~~(3)~~] "Other benefit" means a benefit, other than
12 a benefit under this chapter, to which an individual is entitled for
13 the payment of the costs of services. The term includes:

14 (A) benefits available under:

15 (i) an insurance policy, group health plan,
16 or prepaid medical care plan;

17 (ii) Title XVIII of the Social Security Act
18 (42 U.S.C. Section 1395 et seq.);

19 (iii) Title XIX of the Social Security Act
20 (42 U.S.C. Section 1396 et seq.);

21 (iv) the United States Department of
22 Veterans Affairs;

23 (v) the TRICARE program of the United
24 States Department of Defense; or

25 (vi) workers' compensation or any other
26 compulsory employers insurance program;

27 (B) a public program created by federal or state

1 law or by ordinance or rule of a municipality or political
2 subdivision of the state, except those benefits created by the
3 establishment of a municipal or county hospital, a joint
4 municipal-county hospital, a county hospital authority, a hospital
5 district, or by the facilities of a publicly supported medical
6 school; and

7 (C) benefits resulting from a cause of action for
8 health care expenses, or a settlement or judgment based on the cause
9 of action, if the expenses are related to the need for services
10 provided under this chapter.

11 (7) ~~(4)~~ "Phenylketonuria" means an inherited
12 condition that may cause severe intellectual disability ~~[mental~~
13 ~~retardation]~~ if not treated.

14 (8) ~~(5)~~ "Screening test" means a rapid analytical
15 procedure to determine the need for further diagnostic evaluation.

16 SECTION 3. Sections 33.002(a) and (c), Health and Safety
17 Code, are amended to read as follows:

18 (a) The department shall carry out a program to combat
19 morbidity, including intellectual disability ~~[mental retardation]~~,
20 and mortality in persons who have adrenoleukodystrophy,
21 phenylketonuria, other heritable diseases, or hypothyroidism.

22 (c) The department shall establish and maintain a
23 laboratory to:

24 (1) conduct experiments, projects, and other
25 activities necessary to develop screening or diagnostic tests for
26 the early detection of adrenoleukodystrophy, phenylketonuria,
27 other heritable diseases, and hypothyroidism;

1 (2) develop ways and means or discover methods to be
2 used to prevent or treat adrenoleukodystrophy, phenylketonuria,
3 other heritable diseases, and hypothyroidism; and

4 (3) serve other purposes considered necessary by the
5 department to carry out the program.

6 SECTION 4. Section 33.011(a), Health and Safety Code, is
7 amended to read as follows:

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

14 SECTION 5. Section 33.014(a), Health and Safety Code, is
15 amended to read as follows:

16 (a) If, because of an analysis of a specimen submitted under
17 Section 33.011, the department reasonably suspects that a newborn
18 child may have adrenoleukodystrophy, phenylketonuria, another
19 heritable disease, hypothyroidism, or another disorder for which
20 the screening tests are required, the department shall notify the
21 person who submits the specimen that the results are abnormal and
22 provide the test results to that person. The department may notify
23 one or more of the following that the results of the analysis are
24 abnormal and recommend further testing when necessary:

25 (1) the physician attending the newborn child or the
26 physician's designee;

27 (2) the person attending the delivery of the newborn

1 child that was not attended by a physician;

2 (3) the parents of the newborn child;

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

6 (5) physicians who are cooperating pediatric
7 specialists for the program.

8 SECTION 6. Section 33.031(a), Health and Safety Code, is
9 amended to read as follows:

10 (a) All newborn children and other individuals under 21
11 years of age who have been screened, have been found to be
12 presumptively positive through the newborn screening program for
13 adrenoleukodystrophy, phenylketonuria, other heritable diseases,
14 hypothyroidism, or another disorder for which the screening tests
15 are required, and may be financially eligible may be referred to the
16 department's services program for children with special health care
17 needs.

18 SECTION 7. Section 33.032(a), Health and Safety Code, is
19 amended to read as follows:

20 (a) Within the limits of funds available for this purpose
21 and in cooperation with the individual's physician, the department
22 may provide services directly or through approved providers to
23 individuals of any age who meet the eligibility criteria specified
24 by department rules on the confirmation of a positive test for
25 adrenoleukodystrophy, phenylketonuria, other heritable diseases,
26 hypothyroidism, or another disorder for which the screening tests
27 are required.

SECTION 8. The heading to Chapter 1359, Insurance Code, is amended to read as follows:

CHAPTER 1359. FORMULAS FOR INDIVIDUALS WITH ADRENOLEUKODYSTROPHY, PHENYLKETONURIA, OR OTHER HERITABLE DISEASES

SECTION 9. Section 1359.001, Insurance Code, is amended to read as follows:

Sec. 1359.001. DEFINITIONS. In this chapter:

(1) "Adrenoleukodystrophy" means an inherited condition that results in an abnormality in the structure or function of the brain and causes severe, life-threatening symptoms.

(2) "Heritable disease" means an inherited disease that may result in intellectual ~~[mental]~~ or physical disability ~~[retardation]~~ or death.

(3) ~~[(2)]~~ "Phenylketonuria" means an inherited condition that, if not treated, may cause severe intellectual disability ~~[mental-retardation]~~.

SECTION 10. Section 1359.003(a), Insurance Code, is amended to read as follows:

(a) A group health benefit plan must provide coverage for formulas necessary to treat adrenoleukodystrophy, phenylketonuria, or a heritable disease.

SECTION 11. Section 203.355(c), Occupations Code, is amended to read as follows:

(c) The laboratory services must include the performance of the standard serological tests for syphilis and the collection of blood specimens for newborn screening tests for adrenoleukodystrophy, phenylketonuria, hypothyroidism, and other

1 heritable diseases as required by law.

2 SECTION 12. As soon as practicable after the effective date
3 of this Act, the Department of State Health Services shall
4 implement the changes in law made by this Act to the newborn
5 screening program under Chapter 33, Health and Safety Code.

6 SECTION 13. This Act takes effect September 1, 2017.