By: Meyer

H.B. No. 1067

A BILL TO BE ENTITLED 1 AN ACT 2 relating to newborn screening tests for adrenoleukodystrophy. 3 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF TEXAS: SECTION 1. The heading to Chapter 33, Health and Safety 4 5 Code, is amended to read as follows: CHAPTER 33. ADRENOLEUKODYSTROPHY, PHENYLKETONURIA, OTHER HERITABLE 6 DISEASES, HYPOTHYROIDISM, AND CERTAIN OTHER DISORDERS 7 SECTION 2. Section 33.001, Health and Safety Code, is 8 amended to read as follows: 9 Sec. 33.001. DEFINITIONS. In this chapter: 10 "Adrenoleukodystrophy" means an inherited 11 (1)12 condition that results in an abnormality in the structure or function of the brain and causes severe, life-threatening symptoms. 13 14 (2) "Birthing facility" means an inpatient or ambulatory health care facility that offers obstetrical or newborn 15 16 care services. The term includes: (A) a hospital licensed under Chapter 241 that 17 offers obstetrical services; 18 (B) a birthing center licensed under Chapter 244; 19 20 (C) a children's hospital; or 21 (D) a facility that provides obstetrical services and is maintained and operated by this state or an agency 22 23 of this state. (3) [(1=a)] "Critical congenital heart disease" means 24

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

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

(6) [(3)] "Other benefit" means a benefit, other than 11 12 a benefit under this chapter, to which an individual is entitled for the payment of the costs of services. The term includes: 13 14 (A) benefits available under: 15 (i) an insurance policy, group health plan, or prepaid medical care plan; 16 (ii) Title XVIII of the Social Security Act 17 (42 U.S.C. Section 1395 et seq.); 18 (iii) Title XIX of the Social Security Act 19 (42 U.S.C. Section 1396 et seq.); 20 21 (iv) the United States Department of Veterans Affairs; 22 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 a public program created by federal or state (B)

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 <u>(7)</u> [(4)] "Phenylketonuria" means an inherited 12 condition that may cause severe <u>intellectual disability</u> [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.

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

(a) The department shall carry out a program to combat
morbidity, including <u>intellectual disability</u> [mental retardation],
and mortality in persons who have <u>adrenoleukodystrophy</u>,
phenylketonuria, other heritable diseases, or hypothyroidism.

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

(1) conduct experiments, projects, and other
activities necessary to develop screening or diagnostic tests for
the early detection of <u>adrenoleukodystrophy</u>, phenylketonuria,
other heritable diseases, and hypothyroidism;

(2) develop ways and means or discover methods to be
 used to prevent or treat <u>adrenoleukodystrophy</u>, phenylketonuria,
 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 attending the delivery of a newborn child that is not attended by a 9 physician shall cause the child to be subjected to screening tests 10 approved by the department for adrenoleukodystrophy, 11 phenylketonuria, other heritable diseases, hypothyroidism, and 12 other disorders for which screening is required by the department. 13

SECTION 5. Section 33.014(a), Health and Safety Code, is 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 child may have adrenoleukodystrophy, phenylketonuria, another 18 heritable disease, hypothyroidism, or another disorder for which 19 the screening tests are required, the department shall notify the 20 person who submits the specimen that the results are abnormal and 21 provide the test results to that person. The department may notify 22 23 one or more of the following that the results of the analysis are 24 abnormal and recommend further testing when necessary:

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

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(2) the person attending the delivery of the newborn

1 child that was not attended by a physician;

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(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:

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

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

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

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

CHAPTER 1359. FORMULAS FOR INDIVIDUALS WITH <u>ADRENOLEUKODYSTROPHY</u>,
 PHENYLKETONURIA, OR OTHER HERITABLE DISEASES

5 SECTION 9. Section 1359.001, Insurance Code, is amended to 6 read as follows:

Sec. 1359.001. DEFINITIONS. In this chapter:

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8 (1) <u>"Adrenoleukodystrophy" means an inherited</u> 9 <u>condition that results in an abnormality in the structure or</u> 10 <u>function of the brain and causes severe, life-threatening symptoms.</u> 11 <u>(2)</u> "Heritable disease" means an inherited disease 12 that may result in <u>intellectual</u> [mental] or physical <u>disability</u> 13 [retardation] or death.

14 <u>(3)</u> [(2)] "Phenylketonuria" means an inherited 15 condition that, if not treated, may cause severe <u>intellectual</u> 16 <u>disability</u> [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 <u>adrenoleukodystrophy</u>, 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.