A BILL TO BE ENTITLED 1 AN ACT 2 relating to newborn screening tests for Duchenne muscular dystrophy. 3 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF TEXAS: 4 5 SECTION 1. The heading to Chapter 33, Health and Safety Code, is amended to read as follows: 6 CHAPTER 33. <u>DUCHENNE MUSCULAR DYSTROPHY</u>, PHENYLKETONURIA, OTHER 7 HERITABLE DISEASES, HYPOTHYROIDISM, AND CERTAIN OTHER DISORDERS 8 9 SECTION 2. Section 33.001, Health and Safety Code, is amended by adding Subdivision (6) to read as follows: 10 11 (6) "Duchenne muscular dystrophy" means a progressive 12 muscular degeneration disorder caused by alterations of the protein dystrophin and characterized by progressive muscle degeneration 13 14 and weakness. SECTION 3. Sections 33.002(a) and (c), Health and Safety 15 Code, are amended to read as follows: 16 (a) The department shall carry out a program to combat 17 morbidity, including intellectual disability, and mortality in 18 persons who have Duchenne muscular dystrophy, phenylketonuria, 19 other heritable diseases, or hypothyroidism. 20 21 (c) The department shall establish and maintain а laboratory to: 22 23 (1) conduct experiments, projects, and other 24 activities necessary to develop screening or diagnostic tests for

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the early detection of <u>Duchenne muscular dystrophy</u>,
 phenylketonuria, other heritable diseases, and hypothyroidism;

3 (2) develop ways and means or discover methods to be
4 used to prevent or treat <u>Duchenne muscular dystrophy</u>,
5 phenylketonuria, other heritable diseases, and hypothyroidism; and
6 (3) serve other purposes considered necessary by the

7 department to carry out the program.

8 SECTION 4. Section 33.011(a), Health and Safety Code, is 9 amended to read as follows:

10 (a) The physician attending a newborn child or the person 11 attending the delivery of a newborn child that is not attended by a 12 physician shall cause the child to be subjected to screening tests 13 approved by the department for <u>Duchenne muscular dystrophy,</u> 14 phenylketonuria, other heritable diseases, hypothyroidism, and 15 other disorders for which screening is required by the department.

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

If, because of an analysis of a specimen submitted under 18 (a) 19 Section 33.011, the department reasonably suspects that a newborn child may have Duchenne muscular dystrophy, phenylketonuria, 20 21 another heritable disease, hypothyroidism, or another disorder for which the screening tests are required, the department shall notify 22 23 the person who submits the specimen that the results are abnormal 24 and provide the test results to that person. The department may notify one or more of the following that the results of the analysis 25 26 are abnormal and recommend further testing when necessary:

27 (1) the physician attending the newborn child or the

1 physician's designee;

2 (2) the person attending the delivery of the newborn3 child that was not attended by a physician;

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(3) the parents of the newborn child;

5 (4) the health authority of the jurisdiction in which 6 the newborn child was born or in which the child resides, if known; 7 or

8 (5) physicians who are cooperating pediatric9 specialists for the program.

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

All newborn children and other individuals under 12 (a) 21 years of age who have been screened, have been found to be 13 14 presumptively positive through the newborn screening program for 15 Duchenne muscular dystrophy, phenylketonuria, other heritable diseases, hypothyroidism, or another disorder for which the 16 17 screening tests are required, and may be financially eligible may be referred to the department's services program for children with 18 special health care needs. 19

20 SECTION 7. Section 33.032(a), Health and Safety Code, is 21 amended to read as follows:

(a) Within the limits of funds available for this purpose and in cooperation with the individual's physician, the department may provide services directly or through approved providers to individuals of any age who meet the eligibility criteria specified by department rules on the confirmation of a positive test for <u>Duchenne muscular dystrophy</u>, phenylketonuria, other heritable

1 diseases, hypothyroidism, or another disorder for which the 2 screening tests are required.

3 SECTION 8. Section 203.355(c), Occupations Code, is amended 4 to read as follows:

5 (c) The laboratory services must include the performance of 6 the standard serological tests for syphilis and the collection of 7 blood specimens for newborn screening tests for <u>Duchenne muscular</u> 8 <u>dystrophy</u>, phenylketonuria, hypothyroidism, and other heritable 9 diseases as required by law.

10 SECTION 9. Not later than September 1, 2027, the Department 11 of State Health Services shall implement the changes in law made by 12 this Act to the newborn screening program under Chapter 33, Health 13 and Safety Code.

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SECTION 10. This Act takes effect September 1, 2025.