

By: Parker

S.B. No. 1044

A BILL TO BE ENTITLED

AN ACT

relating to newborn screening tests for Duchenne muscular dystrophy.

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. DUCHENNE MUSCULAR DYSTROPHY, PHENYLKETONURIA, OTHER HERITABLE DISEASES, HYPOTHYROIDISM, AND CERTAIN OTHER DISORDERS

SECTION 2. Section 33.001, Health and Safety Code, is amended by adding Subdivision (6) to read as follows:

(6) "Duchenne muscular dystrophy" means a progressive muscular degeneration disorder caused by alterations of the protein dystrophin and characterized by progressive muscle degeneration and weakness.

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 intellectual disability, and mortality in persons who have Duchenne muscular dystrophy, phenylketonuria, other heritable diseases, or hypothyroidism.

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

(1) conduct experiments, projects, and other activities necessary to develop screening or diagnostic tests for

1 the early detection of Duchenne muscular dystrophy,
2 phenylketonuria, other heritable diseases, and hypothyroidism;

3 (2) develop ways and means or discover methods to be
4 used to prevent or treat Duchenne muscular dystrophy,
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 Duchenne muscular dystrophy,
14 phenylketonuria, other heritable diseases, hypothyroidism, and
15 other disorders for which screening is required by the department.

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

18 (a) If, because of an analysis of a specimen submitted under
19 Section 33.011, the department reasonably suspects that a newborn
20 child may have Duchenne muscular dystrophy, phenylketonuria,
21 another heritable disease, hypothyroidism, or another disorder for
22 which the screening tests are required, the department shall notify
23 the person who submits the specimen that the results are abnormal
24 and provide the test results to that person. The department may
25 notify one or more of the following that the results of the analysis
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 newborn
3 child that was not attended by a physician;

4 (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 pediatric
9 specialists for the program.

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

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

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

22 (a) Within the limits of funds available for this purpose
23 and in cooperation with the individual's physician, the department
24 may provide services directly or through approved providers to
25 individuals of any age who meet the eligibility criteria specified
26 by department rules on the confirmation of a positive test for
27 Duchenne muscular dystrophy, 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 Duchenne muscular
8 dystrophy, 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.

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