BILL ANALYSIS

Senate Research Center

S.B. 1044
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Health & Human Services
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Enrolled

AUTHOR'S / SPONSOR'S STATEMENT OF INTENT

Duchenne muscular dystrophy (DMD) is a universally fatal, rare pediatric disease resulting from an absence of dystrophin—a protein vital for muscle structure, function, and preservation. Its genetic cause is an alteration (mutation) in the DMD gene that provides the code to make dystrophin—that happens before birth and can be inherited or the result of a spontaneous new mutation. Without dystrophin, children with Duchenne experience progressive muscle deterioration and weakness, irreversibly losing the ability to walk, feed themselves, and breathe unassisted over time. Duchenne predominantly affects males, but, in rare cases, can also affect females. One of the most common fatal genetic disorders, DMD affects approximately one in every 3,500–5,000 male births worldwide. Premature death typically occurs in a patient's mid- to late 20s or third decade of life.

Despite advancements in treatment and physician education, the average age of diagnosis for DMD is five years—an average of 2.5 years after parents or caregivers first notice the symptoms of the disease. This lag time in diagnosis has remained unchanged for over 20 years. Many families experience a lengthy, arduous journey to a diagnosis, involving months or years of unnecessary interventions and doctors' visits, with some parents reporting that concerns about their child's development are dismissed. Unfortunately, the diagnostic delay is worse for families of color and families from a low socioeconomic status. Because degeneration begins before birth, patients with Duchenne experience irreversible muscle damage while waiting for a diagnosis. Broad adoption of newborn screening for DMD would prevent unnecessary testing, shorten the time to diagnosis, and help close the gap in racial and ethnic disparities, empowering families to make earlier and better informed treatment decisions.

S.B. 1044 would add screening for DMD to the newborn screening program conducted by the Texas Department of State Health Services (DSHS).

Committee Substitute

- Updates the implementation date from September 1, 2027, to "upon completion of the laboratory."
- Adds that DSHS is required to "implement a provision of this act only if the legislature appropriates money specifically for that purpose."

S.B. 1044 amends current law relating to newborn screening tests for Duchenne muscular dystrophy.

RULEMAKING AUTHORITY

This bill does not expressly grant any additional rulemaking authority to a state officer, institution, or agency.

SECTION BY SECTION ANALYSIS

SECTION 1. Amends the heading to Chapter 33, Health and Safety Code, to read as follows:

CHAPTER 33. DUCHENNE MUSCULAR DYSTROPHY, PHENYLKETONURIA, OTHER HERITABLE DISEASES, HYPOTHYROIDISM, AND CERTAIN OTHER DISORDERS

SECTION 2. Amends Section 33.001, Health and Safety Code, by adding Subdivision (6) to define "Duchenne muscular dystrophy."

SECTION 3. Amends Sections 33.002(a) and (c), Health and Safety Code, as follows:

(a) Requires the Department of State Health Services (DSHS) to carry out a program to combat morbidity, including intellectual disability, and mortality in persons who have Duchenne muscular dystrophy or other heritable diseases.

(c) Makes conforming changes to this subsection.

SECTION 4. Amends Section 33.011(a), Health and Safety Code, to make a conforming change.

SECTION 5. Amends Section 33.014(a), Health and Safety Code, to make a conforming change.

SECTION 6. Amends Section 33.031(a), Health and Safety Code, to make a conforming change.

SECTION 7. Amends Section 33.032(a), Health and Safety Code, to make a conforming change.

SECTION 8. Amends Section 203.355(c), Occupations Code to require that the laboratory services required to be provided under Section 203.355 (Support Services) include the performance of the standard serological tests for syphilis and the collection of blood specimens for newborn screening tests for certain heritable diseases as required by law, including Duchenne muscular dystrophy.

SECTION 9. Requires DSHS, upon completion of the laboratory described by Section 33.002(c) (relating to requiring DSHS to establish and maintain a laboratory to conduct, develop, and serve other necessary purposes to support the detection, prevention, and treatment of certain heritable diseases and conditions), Health and Safety Code, to implement the changes in law made by this Act to the newborn screening program under Chapter 33, Health Code, as amended by this Act.

SECTION 10. Provides that DSHS is required to implement a provision of this Act only if the legislature appropriates money specifically for that purpose. Provides that, if the legislature does not appropriate money specifically for that purpose, DSHS is authorized, but is not required, to implement a provision of this Act using other money available for that purpose.

SECTION 11. Effective date: September 1, 2025.