BILL ANALYSIS

Senate Research Center
89R9499 EAS-F

S.B. 1044
By: Parker
Health & Human Services
3/29/2025
As Filed

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—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 Duchenne 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 Duchenne 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 establish a newborn screening program for DMD.

As proposed, 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 make a conforming change.

SECTION 9. Requires DSHS, not later than September 1, 2027, to implement the changes in law made by this Act to the newborn screening program under Chapter 33, Health and Safety Code.

SECTION 10. Effective date: September 1, 2025.