

BILL ANALYSIS

S.B. 1044
By: Parker
Public Health
Committee Report (Unamended)

BACKGROUND AND PURPOSE

According to the Muscular Dystrophy Association, Duchenne muscular dystrophy (DMD) is a rare pediatric disease resulting from an absence of dystrophin, a protein vital for muscle structure, function, and preservation. Its genetic cause is an in utero alteration in the gene that provides the code to make dystrophin. DMD is typically inherited but sometimes is the result of a spontaneous new mutation. Without dystrophin, children with DMD experience progressive muscle deterioration and weakness, irreversibly losing the ability to walk, feed themselves, and breathe unassisted over time. DMD almost exclusively affects males but, in rare cases, can also affect females. According to Johns Hopkins Medicine, the disease affects approximately one in every 3,500 to 5,000 male births worldwide. DMD most commonly appears in children three to six years old and, despite increased awareness and physician education, the lag time in diagnosis has remained unchanged for over 30 years. The diagnostic delay is worse for families of color and families from a low socioeconomic status. 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 seeks to address this issue by including DMD among the diseases and disorders for which newborn screening is required.

CRIMINAL JUSTICE IMPACT

It is the committee's opinion that this bill does not expressly create a criminal offense, increase the punishment for an existing criminal offense or category of offenses, or change the eligibility of a person for community supervision, parole, or mandatory supervision.

RULEMAKING AUTHORITY

It is the committee's opinion that this bill does not expressly grant any additional rulemaking authority to a state officer, department, agency, or institution.

ANALYSIS

S.B. 1044 amends the Health and Safety Code to include Duchenne muscular dystrophy among the diseases and disorders for which the Department of State Health Services (DSHS) is required to carry out a program to combat morbidity, including intellectual disability, and mortality in persons with such a disease or disorder and establish and maintain a laboratory for certain purposes relating to the early detection, prevention, and treatment of such diseases and disorders. The bill defines "Duchenne muscular dystrophy" as a progressive muscular degeneration disorder caused by alterations of the protein dystrophin and characterized by progressive muscle degeneration and weakness.

S.B. 1044 includes Duchenne muscular dystrophy among the diseases and disorders to which the following statutory provisions apply:

- requirements for newborn screening and related diagnosis and follow-up;
- provisions relating to the referral to the DSHS services program for children with special health care needs of all newborn children and other individuals under 21 years of age who have been screened, have been found positive through the newborn screening program for such a disease or disorder, and may be financially eligible; and
- the authorization for DSHS, in cooperation with the individual's physician, to provide program services directly or through approved providers to individuals of any age who meet the specified eligibility criteria on the confirmation of a positive test for such a disease or disorder.

S.B. 1044 amends the Occupations Code to require the laboratory support services required to be provided by DSHS and a local health department, a public health district, or a local health unit to a pregnant woman or a newborn who is a client of a midwife required to provide services under applicable state law to include the collection of blood specimens for newborn screening tests for Duchenne muscular dystrophy.

S.B. 1044 requires DSHS, upon completion of the laboratory established for certain purposes relating to the early detection, prevention, and treatment of specified diseases and disorders, to implement the bill's changes to provisions relating to the newborn screening program.

S.B. 1044 establishes that DSHS is required to implement a provision of the bill only if the legislature appropriates money specifically for that purpose. If the legislature does not appropriate money specifically for that purpose, DSHS may, but is not required to, implement a provision of the bill using other money available for that purpose.

EFFECTIVE DATE

September 1, 2025.