

# Fiscal Note

**BILL #** SB 1020

**TITLE:** newborn screening; Duchenne muscular dystrophy

**SPONSOR:** Shope

**STATUS:** Senate Engrossed

**PREPARED BY:** Maggie Rocker

## Description

The bill would require the Department of Health Services (DHS) to add Duchenne muscular dystrophy (DMD) to the state's newborn screening panel.

## Estimated Impact

We estimate the bill would generate ongoing costs to DHS of \$684,200 for additional personnel and test processing. We also think the bill would increase DHS's one-time costs by \$204,000 for a validation study. These estimates are based on an analysis provided by the agency. All costs would be paid for by a newborn screening fee increase.

To the extent that DHS raises screening fees to cover the expenses for processing additional tests, costs to the state would increase to pay claims for newborns added to state health insurance plans and state Medicaid plans. Based on the number of newborns added to state health insurance plans and state Medicaid plans each year and DHS's proposed fee increase (\$10), we estimate ongoing state costs would increase by \$129,800. Of this amount, \$116,400 would be paid by the General Fund, and the remaining \$13,400 would be paid by other agency funds.

## Analysis

The Newborn Screening Program centralizes the testing of all newborns in the state for 61 congenital disorders included on the Recommended Uniform Screening Panel (RUSP). Newborns are tested once at about 24 hours of age and again at their first doctor's visit. To process tests at the State Health Lab, DHS collects a \$171 fee for the 2 screening tests. Costs of newborn screening tests are billed to insurance providers or to the newborn's guardian if the newborn is not insured.

The bill would require DHS to add Duchenne muscular dystrophy (DMD), a form of hereditary muscular dystrophy, to the state's newborn screening panel by October 1, 2026, or if earlier, two years from the date DMD is added to the RUSP.

DHS expects the bill to generate \$684,200 in ongoing costs on an annual basis, including laboratory testing costs, 2 FTE Positions, consultation fees, and operating expenses associated with its case management database. In addition to the annual costs, the department estimates one-time costs of \$204,000 for a validation study to ensure the lab equipment and reagents are working appropriately prior to implementation on the screening panel.

To the extent that DHS increases the newborn screening fee to cover the cost of including DMD on the panel, costs to the state would increase for paying screening costs for newborns of benefited state employees and for newborns receiving state Medicaid coverage. DHS estimates it would increase its fees by \$10 in order to fund the costs outlined above. Based on this increased fee level and the number of newborns added to state health insurance plans and state Medicaid plans each year, state costs would increase by \$129,800. Of this amount, \$109,800 would be for state Medicaid General Fund costs, \$6,600 would be for state employee General Fund costs, and \$13,400 would be for state employee costs paid by other agency funds.

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**Local Government Impact**

To the extent that DHS increases the newborn screening fee to cover the cost of including DMD in the newborn screening panel, costs to local governments would increase for paying screening costs of benefited employees and their dependents. The impact by city and county would depend on the number of births to their employees and dependents each year and cannot be determined in advance.

3/1/24