

LEGISLATIVE FISCAL ESTIMATE
SENATE, No. 974
STATE OF NEW JERSEY
218th LEGISLATURE

DATED: JUNE 4, 2019

SUMMARY

Synopsis: Requires newborn infants be screened for spinal muscular atrophy.

Type of Impact: Indeterminate increase in expenditures, offset by an indeterminate increase in revenue; General Fund.

Agencies Affected: Department of Health.

Office of Legislative Services Estimate

Fiscal Impact	<u>Annual</u>
State Cost Increase	Indeterminate
State Revenue Increase	Indeterminate

- The Office of Legislative Services (OLS) estimates that the Department of Health (DOH) would incur an indeterminate amount of expenses to implement the provisions of the bill. These costs may be offset by an indeterminate increase in revenue due to the collection of fees associated with the administration of spinal muscular atrophy (SMA) tests, provided that the department establishes such a fee, as permitted under the bill. The OLS assumes that the provisions of the bill would be integrated into the DOH’s existing newborn screening program, thereby minimizing any costs as well as any need for revenue.

BILL DESCRIPTION

This bill requires all infants born in this State to be tested for the genetic markers associated with SMA, which is a progressive neurodegenerative disease that is caused by abnormally functioning motor neurons that control voluntary movement. Under the bill, the Commissioner of Health is required to develop a comprehensive program of follow-up services and procedures in the event a newborn tests positive for one or more genetic markers associated with spinal muscular atrophy, which, at a minimum is required to provide genetic counseling for certain parents and information concerning available treatment options for spinal muscular atrophy. The DOH may charge a reasonable fee to administer tests performed. The amount of the fee and the procedures for collecting the fee are to be determined by the Commissioner of Health.

FISCAL ANALYSIS

EXECUTIVE BRANCH

None received.

OFFICE OF LEGISLATIVE SERVICES

The OLS estimates that the DOH would incur an indeterminate amount of expenses to implement the provisions of the bill. These costs may be offset by an indeterminate increase in revenue due to the collection of fees associated with the administration of SMA tests, provided that the department establishes such a fee, as permitted under the bill. The OLS assumes that the provisions of the bill would be integrated into the DOH's existing newborn screening program, thereby minimizing any costs as well as any need for revenue.

Existing law requires that every baby born in the State be screened for 55 disorders within 48 hours of birth. A total of 116,000 infants are expected to be screened in FY 2020, which would remain unaffected by the enactment of this bill. It is likely that the existing program could be expanded to include the SMA screening with minimal costs; however, the OLS is unable to quantify such expenses.

Currently, pursuant to N.J.A.C.8:45-2.1, the fee for a newborn screening is \$150. According to the Governor's FY 2020 Budget, the Executive anticipates the department collecting \$3.3 million in revenue for newborn screenings, follow-up, and treatment in FY 2020. The OLS is unable to determine if, and the magnitude to which, the commissioner may choose to establish a fee for SMA screenings, as permitted under the bill, or to increase the existing newborn screen fee. It may be possible that an increase is not necessary, if the expenses incurred to perform the tests are minimal.

Furthermore, statistics suggest that the cost of follow-up services beyond the initial screening may also be minimal due to the size of the affected population. Approximately one in 50 Americans is a carrier of the disease and it is estimated that, in New Jersey, 165,889 people are SMA carriers, 304 are currently living with the disease, and approximately nine babies are born with SMA each year.

Section: *Human Services*

Analyst: *Sarah Schmidt*
 Senior Research Analyst

Approved: *Frank W. Haines III*
 Legislative Budget and Finance Officer

This legislative fiscal estimate has been produced by the Office of Legislative Services due to the failure of the Executive Branch to respond to our request for a fiscal note.

This fiscal estimate has been prepared pursuant to P.L.1980, c.67 (C.52:13B-6 et seq.).