

SENATE BUDGET AND APPROPRIATIONS COMMITTEE

STATEMENT TO

SENATE, No. 974

STATE OF NEW JERSEY

DATED: DECEMBER 5, 2019

The Senate Budget and Appropriations Committee reports favorably Senate Bill No. 974.

This bill requires all infants born in this State to be tested for the genetic markers associated with spinal muscular atrophy (SMA), which is a progressive neurodegenerative disease that is caused by abnormally functioning motor neurons that control voluntary movement, such as walking, talking, and swallowing. SMA leads to progressive muscle weakness and atrophy, particularly in the muscles of the torso, upper legs, and upper arms. The symptoms of SMA typically appear in the first six months of life, although they may manifest later in childhood or, in rare cases, during adulthood. Individuals with the most common form of SMA typically have a lifespan of less than two years. 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.

In December 2016, the federal Food and Drug Administration approved Spinraza (nusinersen) as the first drug approved to treat SMA. Early testing has suggested that diagnosing and treating infants with SMA before they become symptomatic may be the key to successful treatment outcomes, underscoring the importance of early detection of the disease.

FISCAL IMPACT:

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 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.