

SENATE, No. 974

STATE OF NEW JERSEY 218th LEGISLATURE

INTRODUCED JANUARY 16, 2018

Sponsored by:

Senator TROY SINGLETON

District 7 (Burlington)

Senator THOMAS H. KEAN, JR.

District 21 (Morris, Somerset and Union)

Co-Sponsored by:

Senators Cruz-Perez and Diegnan

SYNOPSIS

Requires newborn infants be screened for spinal muscular atrophy.

CURRENT VERSION OF TEXT

As introduced.



(Sponsorship Updated As Of: 5/14/2019)

1 AN ACT concerning screening newborn infants for spinal muscular
2 atrophy and supplementing Title 26 of the Revised Statutes.

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4 **BE IT ENACTED** *by the Senate and General Assembly of the State*
5 *of New Jersey:*

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7 1. a. Each infant born in this State shall be tested for the
8 genetic mutations associated with spinal muscular atrophy.

9 b. The Commissioner of Health shall develop a comprehensive
10 program of follow-up services and procedures in the event a
11 newborn tests positive for one or more genetic markers associated
12 with spinal muscular atrophy, which services and procedures shall
13 include, at a minimum:

14 (1) genetic counseling for the parents of the newborn concerning
15 the risk that one or both parents is a carrier of the genetic mutation
16 associated with spinal muscular atrophy, and the risk that other
17 children born to the parents may carry the mutation, pass it on to
18 their own offspring, or may be born with spinal muscular atrophy;
19 and

20 (2) information concerning available treatment options for
21 spinal muscular atrophy.

22 c. The Department of Health may charge a reasonable fee to
23 administer tests performed pursuant to this section. The amount of
24 the fee and the procedures for collecting the fee shall be determined
25 by the Commissioner of Health.

26 d. The Commissioner of Health shall adopt rules and
27 regulations, pursuant to the "Administrative Procedure Act,"
28 P.L.1968, c.410 (C.52:14B-1 et seq.), necessary to carry out the
29 purposes of this section.

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31 2. This act shall take effect on the 90th day after the date of
32 enactment, except that the Commissioner of Health shall take any
33 anticipatory administrative action in advance thereof as may be
34 necessary to implement the provisions of this act.

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STATEMENT

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

1 lifespan of less than two years. Approximately one in 50
2 Americans is a carrier of the disease, and it is estimated that, in
3 New Jersey, 165,889 people are SMA carriers, 304 are currently
4 living with the disease, and approximately nine babies are born with
5 SMA each year.

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