

# 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, Diegnan and Gopal**

**SYNOPSIS**

Requires newborn infants be screened for spinal muscular atrophy.

**CURRENT VERSION OF TEXT**

As introduced.



**(Sponsorship Updated As Of: 8/26/2019)**

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.