

# STATE OF NEW YORK

3124

2025-2026 Regular Sessions

## IN SENATE

January 23, 2025

Introduced by Sen. ORTT -- read twice and ordered printed, and when printed to be committed to the Committee on Health

AN ACT to amend the public health law, in relation to the testing of newborns for spinal muscular atrophy and public education thereon

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

1 Section 1. Subdivision 1 of section 2500-a of the public health law,  
2 as amended by chapter 730 of the laws of 2021, paragraph (j) as amended  
3 by chapter 70 of the laws of 2022 and paragraph (k) as added by chapter  
4 553 of the laws of 2023, is amended to read as follows:

5 1. It shall be the duty of the administrative officer or other person  
6 in charge of each institution caring for infants twenty-eight days or  
7 less of age and the person required in pursuance of the provisions of  
8 section forty-one hundred thirty of this chapter to register the birth  
9 of a child, to cause to have administered to every such infant or child  
10 in its or his care a test for diseases and conditions designated by the  
11 commissioner under regulations of the commissioner, and for:

12 (a) Phenylketonuria~~[-]~~*;*

13 (b) Homozygous sickle cell disease~~[-]~~*;*

14 (c) Hypothyroidism~~[-]~~*;*

15 (d) Branched-chain ketonuria~~[-]~~*;*

16 (e) Galactosemia~~[-]~~*;*

17 (f) Homocystinuria~~[-]~~*;*

18 (g) Critical congenital heart defects through pulse oximetry screen-  
19 ing~~[-]~~*;*

20 (h) With regard to any newborn infant who is identified as, or  
21 suspected of, having a hearing impairment as a result of a screening  
22 conducted pursuant to section twenty-five hundred-g of this title, a  
23 urine polymerase chain reaction (PCR) test for cytomegalovirus, unless  
24 the parent of the infant objects thereto; provided that if the commis-  
25 sioner determines that another test for cytomegalovirus is diagnos-

EXPLANATION--Matter in *italics* (underscored) is new; matter in brackets  
[-] is old law to be omitted.

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1 tically equivalent to or better than the urine polymerase chain reaction  
2 test, the commissioner may, by regulation under this section, allow or  
3 require the use of that other test[];

4 (i) Adrenoleukodystrophy[];

5 (j) Glucose-6-phosphate dehydrogenase deficiency using a quantitative  
6 enzymatic test or other diagnostic test in cases where: the newborn  
7 infant presents with hemolytic anemia, hemolytic jaundice, or early-on-  
8 set increasing neonatal jaundice, that is, jaundice (bilirubin level  
9 greater than fortieth percentile for age in hours) persisting beyond the  
10 day of birth through the week after birth; the newborn infant has been  
11 admitted to the hospital for jaundice following birth; or the biological  
12 parent of the newborn infant indicates a family, racial, or ethnic risk  
13 of glucose-6-phosphate dehydrogenase deficiency, including having  
14 significant African, Asian, Mediterranean, or Middle Eastern ancestry[  
15 .

16 (k) Duchenne muscular dystrophy using a test validated by the Wads-  
17 worth center for laboratories and research[]; and

18 (l) spinal muscular atrophy.

19 § 2. The public health law is amended by adding a new section 2500-n  
20 to read as follows:

21 § 2500-n. Spinal muscular atrophy public education. 1. The department  
22 shall develop and publish informational materials for women who may  
23 become pregnant, expectant parents and parents of infants regarding:

24 (a) the incidence of spinal muscular atrophy;

25 (b) the risks of spinal muscular atrophy;

26 (c) birth defects caused by spinal muscular atrophy;

27 (d) methods of diagnosing spinal muscular atrophy; and

28 (e) available methods of treating spinal muscular atrophy and  
29 resources available for families of children born with spinal muscular  
30 atrophy.

31 2. The department shall publish the information required pursuant to  
32 subdivision one of this section on its internet website, and distribute  
33 information regarding birth defects, treatment and resources to all  
34 hospitals performing spinal muscular atrophy testing pursuant to section  
35 twenty-five hundred-a of this title.

36 3. The department may promulgate rules to implement the purposes of  
37 this section.

38 § 3. This act shall take effect immediately; except that section one  
39 of this act shall take effect on the one hundred twentieth day after it  
40 shall have become a law. Effective immediately, the addition, amendment  
41 and/or repeal of any rule or regulation necessary for the implementation  
42 of section one of this act on its effective date are authorized to be  
43 made and completed on or before such effective date.