

STATE OF NEW YORK

7048

IN SENATE

(Prefiled)

January 3, 2018

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 (a) of section 2500-a of the public health law,
2 as amended by chapter 184 of the laws of 2013, is amended to read as
3 follows:

4 (a) It shall be the duty of the administrative officer or other person
5 in charge of each institution caring for infants twenty-eight days or
6 less of age and the person required in pursuance of the provisions of
7 section forty-one hundred thirty of this chapter to register the birth
8 of a child, to cause to have administered to every such infant or child
9 in its or his care a test for phenylketonuria, homozygous sickle cell
10 disease, hypothyroidism, branched-chain ketonuria, galactosemia, homo-
11 cystinuria, critical congenital heart defects through pulse oximetry
12 screening, spinal muscular atrophy, and such other diseases and condi-
13 tions as may from time to time be designated by the commissioner in
14 accordance with rules or regulations prescribed by the commissioner.
15 Testing, the recording of the results of such tests, tracking, follow-up
16 reviews and educational activities shall be performed at such times and
17 in such manner as may be prescribed by the commissioner. The commission-
18 er shall promulgate regulations setting forth the manner in which infor-
19 mation describing the purposes of the requirements of this section shall
20 be disseminated to parents or a guardian of the infant tested.

21 § 2. The public health law is amended by adding a new section 2500-1
22 to read as follows:

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

26 (a) the incidence of spinal muscular atrophy;

27 (b) the risks of spinal muscular atrophy;

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

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1 (c) birth defects caused by spinal muscular atrophy;
2 (d) methods of diagnosing spinal muscular atrophy; and
3 (e) available methods of treating spinal muscular atrophy and
4 resources available for families of children born with spinal muscular
5 atrophy.

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

11 3. The department may promulgate rules to implement the purposes of
12 this section.

13 § 3. This act shall take effect immediately; except that section one
14 of this act shall take effect on the one hundred twentieth day after it
15 shall have become a law; provided, however, that effective immediately,
16 the addition, amendment and/or repeal of any rule or regulation neces-
17 sary for the implementation of section one of this act on its effective
18 date are authorized and directed to be made and completed on or before
19 such effective date.