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:

Section 1. Subdivision (a) of section 2500-a of the public health law, as amended by chapter 184 of the laws of 2013, is amended to read as follows:

(a) It shall be the duty of the administrative officer or other person in charge of each institution caring for infants twenty-eight days or less of age and the person required in pursuance of the provisions of section forty-one hundred thirty of this chapter to register the birth of a child, to cause to have administered to every such infant or child in its or his care a test for phenylketonuria, homozygous sickle cell disease, hypothyroidism, branched-chain ketonuria, galactosemia, homocystinuria, critical congenital heart defects through pulse oximetry screening, **spinal muscular atrophy,** and such other diseases and conditions as may from time to time be designated by the commissioner in accordance with rules or regulations prescribed by the commissioner. Testing, the recording of the results of such tests, tracking, follow-up reviews and educational activities shall be performed at such times and in such manner as may be prescribed by the commissioner. The commissioner shall promulgate regulations setting forth the manner in which information describing the purposes of the requirements of this section shall be disseminated to parents or a guardian of the infant tested.

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

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

(a) the incidence of spinal muscular atrophy;

(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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(c) birth defects caused by spinal muscular atrophy;
(d) methods of diagnosing spinal muscular atrophy; and
(e) available methods of treating spinal muscular atrophy and resources available for families of children born with spinal muscular atrophy.
2. The department shall publish the information required pursuant to subdivision one of this section on its internet website, and distribute information regarding birth defects, treatment and resources to all hospitals performing spinal muscular atrophy testing pursuant to section twenty-five hundred-a of this title.
3. The department may promulgate rules to implement the purposes of this section.

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