STATE OF NEW YORK

1654

2023-2024 Regular Sessions

IN SENATE

January 13, 2023

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 1 of section 2500-a of the public health law, as amended by chapter 730 of the laws of 2021, paragraph (j) as amended by chapter 70 of the laws of 2022, is amended to read as follows:

1. 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 diseases and conditions designated by the commissioner under regulations of the commissioner, and for:

(a) Phenylketonuria[~~.~~]*;*

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

(c) Hypothyroidism[~~.~~]*;*

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

(e) Galactosemia[~~.~~]*;*

(f) Homocystinuria[~~.~~]*;*

(g) Critical congenital heart defects through pulse oximetry screening[~~.~~]*;*

(h) With regard to any newborn infant who is identified as, or suspected of, having a hearing impairment as a result of a screening conducted pursuant to section twenty-five hundred-g of this title, a urine polymerase chain reaction (PCR) test for cytomegalovirus, unless the parent of the infant objects thereto; provided that if the commissioner determines that another test for cytomegalovirus is diagnostically equivalent to or better than the urine polymerase chain reaction

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

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test, the commissioner may, by regulation under this section, allow or require the use of that other test[~~.~~];

(i) Adrenoleukodystrophy[~~.~~];

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

(k) spinal muscular atrophy.

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

§ 2500-m. 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;

(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. 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 to be made and completed on or before such effective date.