

# STATE OF NEW YORK

4316

2021-2022 Regular Sessions

## IN SENATE

February 3, 2021

Introduced by Sen. RIVERA -- 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 newborn screening for adrenoleukodystrophy and glucose-6-phosphate dehydrogenase deficiency

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

1 Section 1. Section 2500-a of the public health law, as separately  
2 amended by chapters 943 and 1016 of the laws of 1974, subdivision (a) as  
3 amended by chapter 307 of the laws of 2018 and subdivision (c) as added  
4 by section 113 of part E of chapter 56 of the laws of 2013, is amended  
5 to read as follows:

6 § 2500-a. Test for phenylketonuria and other diseases and conditions.

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

15 [~~i. phenylketonuria,~~  
16 ~~ii. homozygous sickle cell disease,~~  
17 ~~iii. hypothyroidism,~~  
18 ~~iv. branched-chain ketonuria,~~  
19 ~~v. galactosemia,~~  
20 ~~vi. homocystinuria,~~  
21 ~~vii. critical congenital heart defects through pulse oximetry screen-~~  
22 ~~ing,~~  
23 ~~viii. with] (a) Phenylketonuria.  
24 (b) Homozygous sickle cell disease.~~

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

LBD00136-01-1

1 (c) Hypothyroidism.

2 (d) Branched-chain ketonuria.

3 (e) Galactosemia.

4 (f) Homocystinuria.

5 (g) Critical congenital heart defects through pulse oximetry  
6 screening.

7 (h) With regard to any newborn infant who is identified as, or  
8 suspected of, having a hearing impairment as a result of a screening  
9 conducted pursuant to section twenty-five hundred-g of this title,  
10 [~~cause to be administered to such infant~~] a urine polymerase chain  
11 reaction (PCR) test for cytomegalovirus, unless the parent of the infant  
12 objects thereto; provided that if the commissioner determines that  
13 another test for cytomegalovirus is diagnostically equivalent to or  
14 better than the urine polymerase chain reaction test, the commissioner  
15 may, by regulation under this section, allow or require the use of that  
16 other test[, ~~and~~

17 ~~ix, such other diseases and conditions as may from time to time be~~  
18 ~~designated by the commissioner in accordance with rules or regulations~~  
19 ~~prescribed by the commissioner].~~

20 (i) Adrenoleukodystrophy.

21 (j) Glucose-6-phosphate dehydrogenase deficiency.

22 2. Testing, the recording of the results of such tests, tracking,  
23 follow-up reviews and educational activities shall be performed at such  
24 times and in such manner as may be prescribed by the commissioner. The  
25 commissioner shall promulgate regulations setting forth the manner in  
26 which information describing the purposes of the requirements of this  
27 section shall be disseminated to parents or a guardian of the infant  
28 tested.

29 [~~(b)~~] 3. The provisions of this section shall not apply in the case of  
30 any infant or child whose parent or guardian is a member of a recognized  
31 religious organization whose teachings and tenets are contrary to the  
32 testing herein required and who notifies the person charged with having  
33 such test administered of his objection thereto.

34 [~~(c) By regulation, the commissioner shall add adrenoleukodystrophy~~  
35 ~~("ALD") to the list of diseases and conditions for which testing shall~~  
36 ~~be performed pursuant to subdivision (a) of this section upon validation~~  
37 ~~by the Wadsworth Center of a test for ALD. The Wadsworth Center shall~~  
38 ~~undertake the process for validation upon the development of a test.~~  
39 ~~This subdivision shall be known and may be cited as "Aidan's Law."]~~

40 § 2. This act shall take effect on the one hundred eightieth day after  
41 it shall have become a law. Effective immediately, the commissioner of  
42 health shall make regulations and take other actions reasonably neces-  
43 sary to implement this act on that date.