



General Assembly

**Substitute Bill No. 847**

January Session, 2021



**AN ACT CONCERNING NEWBORN INFANT HEALTH SCREENING.**

Be it enacted by the Senate and House of Representatives in General Assembly convened:

1 Section 1. Section 19a-55 of the general statutes is repealed and the  
2 following is substituted in lieu thereof (*Effective October 1, 2021*):

3 (a) The administrative officer or other person in charge of each  
4 institution caring for newborn infants, or a nurse-midwife licensed  
5 pursuant to chapter 377 or midwife shall cause to have administered to  
6 every such newborn infant in its care an HIV-related test, as defined in  
7 section 19a-581, a test for [phenylketonuria and other metabolic  
8 diseases] amino acid disorders, including phenylketonuria, organic acid  
9 disorders, fatty acid oxidation disorders, including, but not limited to,  
10 long-chain 3-hydroxyacyl CoA dehydrogenase (L-CHAD) and  
11 medium-chain acyl-CoA dehydrogenase (MCAD), hypothyroidism,  
12 galactosemia, sickle cell disease, maple syrup urine disease,  
13 homocystinuria, biotinidase deficiency, congenital adrenal hyperplasia,  
14 severe combined immunodeficiency disease, adrenoleukodystrophy  
15 and such other tests for [inborn errors of metabolism as shall be] other  
16 metabolic and genetic disorders included on the recommended uniform  
17 screening panel pursuant to 42 USC 300b-10, as amended from time to  
18 time, as prescribed by the [Department] Commissioner of Public Health.  
19 [The tests shall be administered as soon after birth as is medically

20 appropriate.]

21 (b) The testing requirements prescribed in subsection (a) of this  
22 section shall be performed using a blood spot specimen. The blood spot  
23 specimen shall be collected not earlier than twenty-four hours after the  
24 birth of the newborn infant and not later than forty-eight hours after the  
25 birth of such infant, unless the institution caring for newborn infants,  
26 nurse-midwife licensed pursuant to chapter 377 or midwife determines  
27 that a situation exists to warrant an early collection of the specimen or if  
28 collection of the specimen is medically contraindicated. Situations that  
29 warrant early collection of the specimen shall include, but shall not be  
30 limited to, the imminent transfusion of blood products, dialysis, early  
31 discharge of the newborn infant from the institution, transfer of the  
32 newborn infant to another institution or imminent death. If the newborn  
33 infant dies before a blood spot specimen can be obtained, the specimen  
34 shall be collected as soon as practicable after death. The institution  
35 licensed to care for newborn infants, nurse-midwife or midwife shall  
36 notify the Department of Public Health when a specimen is not collected  
37 within forty-eight hours after the birth of such infant due to: (1) The  
38 infant's medical fragility, (2) refusal by the parents when newborn infant  
39 screening is in conflict with their religious tenets and practice, (3) the  
40 newborn infant receiving comfort measures only, or (4) any other  
41 reason. Such notification shall be documented in the department's  
42 newborn screening system pursuant to section 19a-53 by the institution  
43 caring for newborn infants, nurse-midwife or midwife, or sent in  
44 writing to the department not later than seventy-two hours after the  
45 birth of the newborn infant. The institution caring for newborn infants,  
46 nurse-midwife or midwife shall send the blood spot specimen to the  
47 state public health laboratory not later than twenty-four hours after the  
48 time of collection. The department may request an additional blood spot  
49 specimen if: (A) There was an early collection of the specimen, (B) the  
50 specimen was collected following a transfusion of blood products, (C)  
51 the specimen is unsatisfactory for testing, or (D) the department  
52 determines that there is an abnormal result. If the mother has had an  
53 HIV-related test pursuant to section 19a-90 or 19a-593, the person

54 responsible for testing under this section may omit an HIV-related test.

55 (c) The Commissioner of Public Health shall (1) administer the  
56 newborn screening program, (2) direct persons identified through the  
57 screening program to appropriate specialty centers for treatments,  
58 consistent with any applicable confidentiality requirements, and (3) set  
59 the fees to be charged to institutions to cover all expenses of the  
60 comprehensive screening program including testing, tracking and  
61 treatment. The fees to be charged pursuant to subdivision (3) of this  
62 subsection shall be set at a minimum of ninety-eight dollars. The  
63 Commissioner of Public Health shall publish a list of all the abnormal  
64 conditions for which the department screens newborns under the  
65 newborn screening program, [ which shall include screening for amino  
66 acid disorders, organic acid disorders, fatty acid oxidation disorders,  
67 including, but not limited to, long-chain 3-hydroxyacyl CoA  
68 dehydrogenase (L-CHAD) and medium-chain acyl-CoA  
69 dehydrogenase (MCAD), and, subject to the approval of the Secretary  
70 of the Office of Policy and Management, any other disorder included on  
71 the recommended uniform screening panel pursuant to 42 USC 300b-10,  
72 as amended from time to time.]

73 [(b)] (d) In addition to the testing requirements prescribed in  
74 subsection (a) of this section, the administrative officer or other person  
75 in charge of each institution caring for newborn infants, or a licensed  
76 nurse-midwife or midwife, shall cause to have administered to (1) every  
77 such infant in its care a screening test for (A) cystic fibrosis, and (B)  
78 critical congenital heart disease, [and (C) on and after January 1, 2020,  
79 spinal muscular atrophy,] and (2) any newborn infant who fails a  
80 newborn hearing screening, as described in section 19a-59, a screening  
81 test for cytomegalovirus, provided such screening test shall be  
82 administered within available appropriations. The administrative  
83 officer or other person in charge of each institution caring for newborn  
84 infants who performs the testing for critical congenital heart disease  
85 shall enter the results of such test into the newborn screening system  
86 pursuant to section 19a-53. The administrative officer or other person in

