



General Assembly

February Session, 2020

**Raised Bill No. 373**

LCO No. 1892



Referred to Committee on PUBLIC HEALTH

Introduced by:  
(PH)

***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 2020 supplement to the general  
2 statutes is repealed and the following is substituted in lieu thereof  
3 (*Effective October 1, 2020*):

4 (a) The administrative officer or other person in charge of each  
5 institution caring for newborn infants shall cause to have administered  
6 to every such newborn infant in its care an HIV-related test, as defined  
7 in 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] other metabolic  
16 and genetic disorders included on the recommended uniform screening

17 panel pursuant to 42 USC 300b-10, as amended from time to time, as  
18 [shall be] prescribed by the [Department] Commissioner of Public  
19 Health, [. The tests shall be administered as soon after birth as is  
20 medically appropriate] and subject to the approval of the Secretary of  
21 the Office of Policy and Management.

22 (b) The testing requirements prescribed in subsection (a) of this  
23 section shall be performed using a blood spot specimen. The blood spot  
24 specimen shall be collected no earlier than twenty-four hours after the  
25 birth of the newborn infant and not later than forty-eight hours after the  
26 birth of such infant, unless the institution determines that a situation  
27 exists to warrant an early collection of the specimen or if collection of  
28 the specimen is medically contraindicated. Situations that warrant early  
29 collection of the specimen shall include, but shall not be limited to, the  
30 imminent transfusion of blood products, dialysis, early discharge of the  
31 newborn infant, transfer of the newborn infant to another institution, or  
32 imminent death. If the newborn infant dies before a blood spot specimen  
33 can be obtained, the specimen shall be collected as soon as practicable  
34 after death. The institution licensed to care for newborn infants, or a  
35 licensed nurse-midwife or midwife, shall notify the Department of  
36 Public Health when a specimen is not collected within forty-eight hours  
37 of birth due to medical fragility, refusal by the parents when newborn  
38 infant screening is in conflict with their religious tenents and practice,  
39 when a newborn infant is receiving comfort measures only, or for any  
40 other reason. Such notification shall be documented in the department's  
41 newborn screening system pursuant to section 19a-53 by the institution  
42 caring for newborn infants, nurse-midwife or midwife, or sent in  
43 writing to the department not later than seventy-two hours after the  
44 birth of the newborn infant. The institution caring for newborn infants  
45 or the nurse-midwife or midwife shall send the blood spot specimen to  
46 the state public health laboratory not later than twenty-four hours after  
47 the time of collection. The department may request an additional blood  
48 spot specimen if there was an early collection of the specimen or if the  
49 specimen was collected following a transfusion of blood products, if the  
50 specimen is unsatisfactory for testing or if the department determines

51 that there is an abnormal result. If the mother has had an HIV-related  
52 test pursuant to section 19a-90 or 19a-593, the person responsible for  
53 testing under this section may omit an HIV-related test.

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

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

85 pursuant to section 19a-53. The administrative officer or other person in  
86 charge of each institution who performs the testing for cystic fibrosis  
87 shall report the number of newborn infants screened and the aggregate  
88 results of such testing on an annual basis to the Department of Public  
89 Health, in a form and manner prescribed by the Commissioner of Public  
90 Health. The provisions of this section shall apply irrespective of the  
91 patient's insurance status or source of payment, including self-pay  
92 status. Such screening tests shall be administered as soon after birth as  
93 is medically appropriate.

94 [(c)] (e) The administrative officer or other person in charge of each  
95 institution caring for newborn infants shall report any case of  
96 cytomegalovirus that is confirmed as a result of a screening test  
97 administered pursuant to subdivision (2) of subsection [(b)] (d) of this  
98 section to the Department of Public Health in a form and manner  
99 prescribed by the Commissioner of Public Health.

100 [(d)] (f) The provisions of this section shall not apply to any infant  
101 whose parents object to the test or treatment as being in conflict with  
102 their religious tenets and practice. The commissioner shall adopt  
103 regulations, in accordance with the provisions of chapter 54, to  
104 implement the provisions of this section.

This act shall take effect as follows and shall amend the following sections:		
Section 1	October 1, 2020	19a-55

**Statement of Purpose:**

To require health screening of newborn infants no earlier than twenty-four hours after the birth of the newborn infant and not later than forty-eight hours after the birth of such infant and to add various metabolic and genetic disorders to the newborn infant screening panel.

*[Proposed deletions are enclosed in brackets. Proposed additions are indicated by underline, except that when the entire text of a bill or resolution or a section of a bill or resolution is new, it is not underlined.]*