



General Assembly

February Session, 2014

Raised Bill No. 5147

LCO No. 999



Referred to Committee on PUBLIC HEALTH

Introduced by:
(PH)

AN ACT CONCERNING NEWBORN SCREENING FOR GLOBOID CELL LEUKODYSTROPHY AND CYTOMEGALOVIRUS AND ESTABLISHING A PUBLIC EDUCATION PROGRAM FOR CYTOMEGALOVIRUS.

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

1 Section 1. Section 19a-55 of the 2014 supplement to the general
2 statutes is repealed and the following is substituted in lieu thereof
3 (*Effective July 1, 2014*):

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 infant in its care an HIV-related test, as defined in section
7 19a-581, a test for phenylketonuria and other metabolic diseases,
8 hypothyroidism, galactosemia, sickle cell disease, maple syrup urine
9 disease, homocystinuria, biotinidase deficiency, congenital adrenal
10 hyperplasia and such other tests for inborn errors of metabolism as
11 shall be prescribed by the Department of Public Health. The tests shall
12 be administered as soon after birth as is medically appropriate. If the
13 mother has had an HIV-related test pursuant to section 19a-90 or 19a-
14 593, the person responsible for testing under this section may omit an

15 HIV-related test. The Commissioner of Public Health shall (1)
16 administer the newborn screening program, (2) direct persons
17 identified through the screening program to appropriate specialty
18 centers for treatments, consistent with any applicable confidentiality
19 requirements, and (3) set the fees to be charged to institutions to cover
20 all expenses of the comprehensive screening program including
21 testing, tracking and treatment. The fees to be charged pursuant to
22 subdivision (3) of this subsection shall be set at a minimum of fifty-six
23 dollars. The Commissioner of Public Health shall publish a list of all
24 the abnormal conditions for which the department screens newborns
25 under the newborn screening program, which shall include screening
26 for amino acid disorders, organic acid disorders and fatty acid
27 oxidation disorders, including, but not limited to, long-chain 3-
28 hydroxyacyl CoA dehydrogenase (L-CHAD) and medium-chain acyl-
29 CoA dehydrogenase (MCAD).

30 (b) In addition to the testing requirements prescribed in subsection
31 (a) of this section, the administrative officer or other person in charge
32 of each institution caring for newborn infants shall cause to have
33 administered to (1) every such infant in its care [(1)] (A) a screening
34 test for cystic fibrosis, [(2)] (B) a screening test for severe combined
35 immunodeficiency disease, [and (3) on and after January 1, 2013,] (C) a
36 screening test for critical congenital heart disease, and (D) on and after
37 January 1, 2015, a screening test for globoid cell leukodystrophy; and
38 (2) on and after January 1, 2015, any newborn infant who fails a
39 newborn hearing screening as described in section 19a-59, a screening
40 test for cytomegalovirus. Such screening tests shall be administered as
41 soon after birth as is medically appropriate.

42 (c) On and after the occurrence of the following: (1) The
43 development and validation of a reliable methodology for screening
44 newborns for adrenoleukodystrophy using dried blood spots and
45 quality assurance testing methodology for such test or the approval of
46 a test for adrenoleukodystrophy using dried blood spots by the federal
47 Food and Drug Administration; and (2) the availability of any

48 necessary reagents for such test, the administrative officer or other
49 person in charge of each institution caring for newborn infants shall
50 cause to have administered to every such infant in its care a test for
51 adrenoleukodystrophy.

52 (d) The provisions of this section shall not apply to any infant whose
53 parents object to the test or treatment as being in conflict with their
54 religious tenets and practice. The commissioner shall adopt
55 regulations, in accordance with the provisions of chapter 54, to
56 implement the provisions of this section.

57 Sec. 2. (NEW) (*Effective July 1, 2014*) (a) The Commissioner of Public
58 Health shall establish a public education program to inform pregnant
59 women and women who may become pregnant concerning: (1) The
60 incidence of cytomegalovirus; (2) transmission of cytomegalovirus to
61 pregnant women and women who may become pregnant; (3) birth
62 defects caused by congenital cytomegalovirus; (4) methods of
63 diagnosing congenital cytomegalovirus; (5) measures to prevent
64 transmission of cytomegalovirus; and (6) methods of treating
65 congenital cytomegalovirus. The commissioner shall make such
66 information available to child day care centers and group day care
67 homes, licensed in accordance with section 19a-80 of the general
68 statutes, licensed health care providers who provide services to
69 pregnant women and infants, school nurses and other persons
70 providing health education in schools, and other organizations
71 providing services to children in a group setting.

72 (b) The administrative officer or other person in charge of an
73 institution that administers a newborn screening test for
74 cytomegalovirus in accordance with section 19a-55 of the general
75 statutes, as amended by this act, shall provide the parent of such
76 newborn information obtained from the Commissioner of Public
77 Health concerning birth defects caused by congenital cytomegalovirus
78 and available methods of treating congenital cytomegalovirus.

This act shall take effect as follows and shall amend the following sections:		
Section 1	<i>July 1, 2014</i>	19a-55
Sec. 2	<i>July 1, 2014</i>	New section

Statement of Purpose:

To require newborn screening for globoid cell leukodystrophy and cytomegalovirus and to establish a public education program for cytomegalovirus.

[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.]