



General Assembly

**Substitute Bill No. 5147**

February Session, 2014



**AN ACT CONCERNING NEWBORN SCREENING FOR  
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2 statutes is repealed and the following is substituted in lieu thereof  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 (2) on and after  
37 January 1, 2015, any newborn infant who fails a newborn hearing  
38 screening as described in section 19a-59, a screening test for  
39 cytomegalovirus. Such screening tests shall be administered as soon  
40 after birth as is medically appropriate.

41 (c) On and after the occurrence of the following: (1) The  
42 development and validation of a reliable methodology for screening  
43 newborns for adrenoleukodystrophy using dried blood spots and  
44 quality assurance testing methodology for such test or the approval of  
45 a test for adrenoleukodystrophy using dried blood spots by the federal  
46 Food and Drug Administration; and (2) the availability of any  
47 necessary reagents for such test, the administrative officer or other  
48 person in charge of each institution caring for newborn infants shall  
49 cause to have administered to every such infant in its care a test for  
50 adrenoleukodystrophy.

51 (d) The provisions of this section shall not apply to any infant whose  
52 parents object to the test or treatment as being in conflict with their

53 religious tenets and practice. The commissioner shall adopt  
54 regulations, in accordance with the provisions of chapter 54, to  
55 implement the provisions of this section.

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

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

**PH**           *Joint Favorable Subst.*