



General Assembly

**Substitute Bill No. 5525**

January Session, 2015



**AN ACT CONCERNING CYTOMEGALOVIRUS.**

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 Section 19a-55 of the general statutes is repealed and the  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 July 1, 2015*):

3 (a) The administrative officer or other person in charge of each  
4 institution caring for newborn infants shall cause to have administered  
5 to every such infant in its care an HIV-related test, as defined in section  
6 19a-581, a test for phenylketonuria and other metabolic diseases,  
7 hypothyroidism, galactosemia, sickle cell disease, maple syrup urine  
8 disease, homocystinuria, biotinidase deficiency, congenital adrenal  
9 hyperplasia and such other tests for inborn errors of metabolism as  
10 shall be prescribed by the Department of Public Health. The tests shall  
11 be administered as soon after birth as is medically appropriate. If the  
12 mother has had an HIV-related test pursuant to section 19a-90 or 19a-  
13 593, the person responsible for testing under this section may omit an  
14 HIV-related test. The Commissioner of Public Health shall (1)  
15 administer the newborn screening program, (2) direct persons  
16 identified through the screening program to appropriate specialty  
17 centers for treatments, consistent with any applicable confidentiality  
18 requirements, and (3) set the fees to be charged to institutions to cover  
19 all expenses of the comprehensive screening program including  
20 testing, tracking and treatment. The fees to be charged pursuant to

21 subdivision (3) of this subsection shall be set at a minimum of fifty-six  
22 dollars. The Commissioner of Public Health shall publish a list of all  
23 the abnormal conditions for which the department screens newborns  
24 under the newborn screening program, which shall include screening  
25 for amino acid disorders, organic acid disorders and fatty acid  
26 oxidation disorders, including, but not limited to, long-chain 3-  
27 hydroxyacyl CoA dehydrogenase (L-CHAD) and medium-chain acyl-  
28 CoA dehydrogenase (MCAD).

29 (b) In addition to the testing requirements prescribed in subsection  
30 (a) of this section, the administrative officer or other person in charge  
31 of each institution caring for newborn infants shall cause to have  
32 administered to (1) every such infant in its care [(1)] a screening test for  
33 (A) cystic fibrosis, [(2) a screening test for] (B) severe combined  
34 immunodeficiency disease, and [(3) on and after January 1, 2013, a  
35 screening test for] (C) critical congenital heart disease, and (2) any  
36 newborn infant who fails a newborn hearing screening, as described in  
37 section 19a-59, a screening test for cytomegalovirus, provided such  
38 screening test shall be administered within available appropriations on  
39 and after January 1, 2016. Such screening tests shall be administered as  
40 soon 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.

This act shall take effect as follows and shall amend the following sections:		
Section 1	<i>July 1, 2015</i>	19a-55

**Statement of Legislative Commissioners:**

In Section 1(b)(1), "on and after January 1, 2013," was included in bracketed text for clarity. In addition, Section 1(b)(2) was redrafted for clarity.

**PH**            *Joint Favorable Subst. -LCO*