



House of Representatives

General Assembly

File No. 494

February Session, 2014

Substitute House Bill No. 5147

House of Representatives, April 10, 2014

The Committee on Public Health reported through REP. JOHNSON of the 49th Dist., Chairperson of the Committee on the part of the House, that the substitute bill ought to pass.

***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2 statutes is repealed and the following is substituted in lieu thereof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.*

The following Fiscal Impact Statement and Bill Analysis are prepared for the benefit of the members of the General Assembly, solely for purposes of information, summarization and explanation and do not represent the intent of the General Assembly or either chamber thereof for any purpose. In general, fiscal impacts are based upon a variety of informational sources, including the analyst's professional knowledge. Whenever applicable, agency data is consulted as part of the analysis, however final products do not necessarily reflect an assessment from any specific department.

OFA Fiscal Note

State Impact:

Agency Affected	Fund-Effect	FY 15 \$	FY 16 \$
Public Health, Dept.	GF - Cost	approx. 40,000	approx. 27,000

Municipal Impact: None

Explanation

The bill results in a cost to the Department of Public Health (DPH) of approximately \$40,000 in FY 15 and approximately \$27,000 in FY 16 to establish a cytomegalovirus public education program. Costs to DPH reflect the on-going publishing and distribution expenses for 155,000 English-language brochures, 16,000 Spanish-language brochures and 8,000 English-language/500 Spanish-language posters. These are anticipated to be distributed to various health care providers, daycares and school nurses. There is an anticipated one-time cost to DPH of \$14,000 in FY 15 associated with the development and design of the brochure and poster. FY 16 printing costs were inflated by 2.1% and mailing costs were inflated by 6.5%.¹ It is anticipated that DPH will also post information about cytomegalovirus on its website. There is no fiscal impact to DPH to post information on its website. Cytomegalovirus testing for infants that fail their hearing screening will be performed by the institutions that administer newborn screening tests, not by DPH and, therefore, there will be no cost to DPH from these tests.

The Out Years

¹This is the percent increase in the United States Postal Services postage stamps from 1/27/13 (\$0.42) to 1/26/14 (\$0.49).

The annualized ongoing fiscal impact identified above would continue into the future subject to inflation.

Sources: United States Postal Service online: Postage Rates and Historical Statistics

OLR Bill Analysis**sHB 5147*****AN ACT CONCERNING NEWBORN SCREENING FOR CYTOMEGALOVIRUS AND ESTABLISHING A PUBLIC EDUCATION PROGRAM FOR CYTOMEGALOVIRUS.*****SUMMARY:**

Beginning January 1, 2015, this bill requires all healthcare institutions caring for newborn infants to (1) test infants who fail a newborn hearing screening for cytomegalovirus (CMV), and (2) provide parents of such newborns with information from the public health commissioner regarding available treatment methods for, and birth defects associated with, congenital CMV. As with other newborn screenings required by law, the CMV screening must be done as soon after birth as medically appropriate and parents may object to the test on religious grounds.

The bill also requires the public health commissioner to create a public education program to inform pregnant women, and women who may become pregnant, about CMV. Specifically, the program must include information on the (1) incidence of CMV; (2) transmission of CMV to pregnant women and women who may become pregnant; (3) birth defects caused by congenital CMV; and (4) methods of diagnosing, preventing, and treating congenital CMV.

The commissioner must make the information available to licensed day care centers and group day care homes, licensed health care providers who serve pregnant women and infants, school nurses and others providing health education in schools, and other organizations providing services to children in a group setting.

EFFECTIVE DATE: July 1, 2014

BACKGROUND

CMV

CMV is a type of herpesvirus, which places it in a group with chickenpox, shingles, and mononucleosis. Although usually harmless in healthy adults and children, CMV in newborns can lead to hearing loss or developmental disabilities. Transmission from mother to fetus occurs during pregnancy.

COMMITTEE ACTION

Public Health Committee

Joint Favorable Substitute

Yea 25 Nay 0 (03/25/2014)