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:

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 Section 19a-55 of the 2014 supplement to the general statutes is repealed and the following is substituted in lieu thereof (Effective July 1, 2014):

(a) The administrative officer or other person in charge of each institution caring for newborn infants shall cause to have administered to every such infant in its care an HIV-related test, as defined in section 19a-581, a test for phenylketonuria and other metabolic diseases, hypothyroidism, galactosemia, sickle cell disease, maple syrup urine disease, homocystinuria, biotinidase deficiency, congenital adrenal hyperplasia and such other tests for inborn errors of metabolism as shall be prescribed by the Department of Public Health. The tests shall be administered as soon after birth as is medically appropriate. If the mother has had an HIV-related test pursuant to section 19a-90 or 19a-593, the person responsible for testing under this section may omit an
HIV-related test. The Commissioner of Public Health shall (1) administer the newborn screening program, (2) direct persons identified through the screening program to appropriate specialty centers for treatments, consistent with any applicable confidentiality requirements, and (3) set the fees to be charged to institutions to cover all expenses of the comprehensive screening program including testing, tracking and treatment. The fees to be charged pursuant to subdivision (3) of this subsection shall be set at a minimum of fifty-six dollars. The Commissioner of Public Health shall publish a list of all the abnormal conditions for which the department screens newborns under the newborn screening program, which shall include screening for amino acid disorders, organic acid disorders and fatty acid oxidation disorders, including, but not limited to, long-chain 3-hydroxyacyl CoA dehydrogenase (L-CHAD) and medium-chain acyl-CoA dehydrogenase (MCAD).

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

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

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

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

(b) The administrative officer or other person in charge of an
institution that administers a newborn screening test for
cytomegalovirus in accordance with section 19a-55 of the general
statutes, as amended by this act, shall provide the parent of such
newborn information obtained from the Commissioner of Public
Health concerning birth defects caused by congenital cytomegalovirus
and available methods of treating congenital cytomegalovirus.
This act shall take effect as follows and shall amend the following sections:

<table>
<thead>
<tr>
<th>Section</th>
<th>Date</th>
<th>Amendment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>July 1, 2014</td>
<td>19a-55</td>
</tr>
<tr>
<td>2</td>
<td>July 1, 2014</td>
<td>New section</td>
</tr>
</tbody>
</table>

**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.]