



House of Representatives

General Assembly

File No. 560

January Session, 2019

House Bill No. 7282

House of Representatives, April 9, 2019

The Committee on Public Health reported through REP. STEINBERG of the 136th Dist., Chairperson of the Committee on the part of the House, that the bill ought to pass.

AN ACT CONCERNING NEWBORN SCREENING FOR SPINAL MUSCULAR ATROPHY.

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 Section 19a-55 of the general statutes is repealed and the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 October 1, 2019*):

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, severe combined immunodeficiency disease,
10 adrenoleukodystrophy and such other tests for inborn errors of
11 metabolism as shall be prescribed by the Department of Public Health.
12 The tests shall be administered as soon after birth as is medically
13 appropriate. If the mother has had an HIV-related test pursuant to
14 section 19a-90 or 19a-593, the person responsible for testing under this

15 section may omit an HIV-related test. The Commissioner of Public
16 Health shall (1) administer the newborn screening program, (2) direct
17 persons identified through the screening program to appropriate
18 specialty centers for treatments, consistent with any applicable
19 confidentiality requirements, and (3) set the fees to be charged to
20 institutions to cover all expenses of the comprehensive screening
21 program including testing, tracking and treatment. The fees to be
22 charged pursuant to subdivision (3) of this subsection shall be set at a
23 minimum of ninety-eight dollars. The Commissioner of Public Health
24 shall publish a list of all the abnormal conditions for which the
25 department screens newborns under the newborn screening program,
26 which shall include screening for amino acid disorders, organic acid
27 disorders and fatty acid oxidation disorders, including, but not limited
28 to, long-chain 3-hydroxyacyl CoA dehydrogenase (L-CHAD) and
29 medium-chain acyl-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 a screening test for (A)
34 cystic fibrosis, [and] (B) critical congenital heart disease, and (C) on
35 and after January 1, 2020, spinal muscular atrophy, 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.
39 [on and after January 1, 2016. On and after January 1, 2018, the] The
40 administrative officer or other person in charge of each institution
41 caring for newborn infants who performs the testing for critical
42 congenital heart disease shall enter the results of such test into the
43 newborn screening system pursuant to section 19a-53. Such screening
44 tests shall be administered as soon after birth as is medically
45 appropriate.

46 (c) The administrative officer or other person in charge of each
47 institution caring for newborn infants shall report any case of
48 cytomegalovirus that is confirmed as a result of a screening test

49 administered pursuant to subdivision (2) of subsection (b) of this
50 section to the Department of Public Health in a form and manner
51 prescribed by the Commissioner of Public Health.

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.

This act shall take effect as follows and shall amend the following sections:		
Section 1	<i>October 1, 2019</i>	19a-55

PH *Joint Favorable*

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 20 \$	FY 21 \$
Public Health, Dept.	GF - Cost	less than 2,500	less than 5,000

Note: GF=General Fund

Municipal Impact: None

Explanation

The bill, which requires that all newborns be tested for spinal muscular atrophy starting 1/1/20, results in a cost to the Department of Public Health of less than \$2,500 in FY 20 (half-year) and less than \$5,000 in FY 21 (full-year) for test reagents. This estimate assumes approximately 36,000 live births annually.¹ The cost for this test could be recouped if the fee per newborn screened were increased by approximately \$0.13.

The Out Years

The annualized ongoing fiscal impact identified above would continue into the future subject to the cost of testing and the number of newborns screened.

Sources: Department of Public Health, Office of Vital Statistics
<https://portal.ct.gov/dph/Health-Information-Systems--Reporting/Hisrhome/Vital-Statistics-Registration-Reports>

¹There were 35,673 live births in Connecticut in 2015.

OLR Bill Analysis**HB 7282*****AN ACT CONCERNING NEWBORN SCREENING FOR SPINAL MUSCULAR ATROPHY.*****SUMMARY**

Starting January 1, 2020, this bill requires all health care institutions caring for newborn infants to test them for spinal muscular atrophy, unless a parent objects based on religious grounds. It requires the testing to be done as soon as is medically appropriate.

Like existing law that requires these institutions to test newborn infants for cystic fibrosis and critical congenital heart disease, the test for spinal muscular atrophy is not part of the state's newborn screening program for genetic and metabolic disorders. That program, in addition to screening, directs parents of identified infants to counseling and treatment.

EFFECTIVE DATE: October 1, 2019

BACKGROUND***Spinal Muscular Atrophy***

Spinal muscular atrophy is a genetic disease affecting the part of the nervous system that controls voluntary muscle movement. Specifically, it is a motor neuron disease that involves the loss of nerve cells in the spinal cord that may affect a person's ability to walk, eat, or breathe, among other things. The earlier the age of onset, the greater the affect the disease has on a person's motor function.

COMMITTEE ACTION

Public Health Committee

Joint Favorable

Yea 21 Nay 0 (03/22/2019)