



House of Representatives

General Assembly

File No. 453

January Session, 2015

House Bill No. 5271

House of Representatives, April 7, 2015

The Committee on Public Health reported through REP. RITTER of the 1st Dist., Chairperson of the Committee on the part of the House, that the bill ought to pass.

AN ACT CONCERNING NEWBORN SCREENING AND A PUBLIC EDUCATION PROGRAM FOR GLOBOID CELL LEUKODYSTROPHY.

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 Section 19a-55 of the general statutes is repealed and the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 January 1, 2016*):

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 every such infant in its care, [(1)] a screening test for
33 (1) cystic fibrosis, [(2) a screening test for] (2) severe combined
34 immunodeficiency disease, and [(3) on and after January 1, 2013, a
35 screening test for] (3) critical congenital heart disease. Such screening
36 tests shall be administered as soon after birth as is medically
37 appropriate.

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

48 (d) Not later than six months after the date on which the United
49 States Department of Health and Human Services' Discretionary
50 Advisory Committee on Heritable Disorders in Newborns and
51 Children includes globoid cell leukodystrophy in its uniform screening
52 panel, the administrative officer or other person in charge of each
53 institution caring for newborn infants shall cause to have administered
54 to every such infant in its care, within available appropriations, a test
55 for globoid cell leukodystrophy.

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

61 Sec. 2. (NEW) (*Effective July 1, 2015*) (a) The Commissioner of Public
62 Health shall establish, within available appropriations, a public
63 education program to inform pregnant women and women who may
64 become pregnant concerning: (1) The incidence of globoid cell
65 leukodystrophy; (2) birth defects caused by globoid cell
66 leukodystrophy; (3) methods of diagnosing globoid cell
67 leukodystrophy; and (4) methods of treating globoid cell
68 leukodystrophy. The commissioner shall make such information
69 available to child day care centers and group day care homes, licensed
70 in accordance with section 19a-80 of the general statutes, licensed
71 health care providers who provide services to pregnant women and
72 infants, school nurses and other persons providing health education in
73 schools, and other organizations providing services to children in a
74 group setting.

75 (b) The administrative officer or other person in charge of an
76 institution that administers a newborn screening test for globoid cell
77 leukodystrophy in accordance with section 19a-55 of the general
78 statutes, as amended by this act, shall provide the parent of a newborn
79 information obtained from the Commissioner of Public Health
80 concerning birth defects caused by globoid cell leukodystrophy and

81 available methods of treating globoid cell leukodystrophy.

This act shall take effect as follows and shall amend the following sections:		
Section 1	<i>January 1, 2016</i>	19a-55
Sec. 2	<i>July 1, 2015</i>	New section

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 16 \$	FY 17 \$
Public Health, Dept.	GF - Potential Cost	39,000	26,000

Note: GF=General Fund

Municipal Impact: None

Explanation

The bill may result in a cost of \$39,000 in FY 16 and \$26,000 in FY 17 to the Department of Public Health (DPH) to establish a public education program to inform women about Globoid Cell Leukodystrophy (GCL) in various locations. The cost will only occur if the federal government includes GCL in its uniform screen panel. The DPH costs are associated with developing and designing brochures, printing in Spanish and English and mailings to healthcare providers, hospital providers and daycare providers.

No net impact is anticipated for the UConn Health Center (UCHC) from requiring hospitals to test newborns for GCL. Although UCHC may incur additional costs from testing, any such costs should be recouped through third-party billing.

The Out Years

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

OLR Bill Analysis**HB 5271*****AN ACT CONCERNING NEWBORN SCREENING AND A PUBLIC EDUCATION PROGRAM FOR GLOBOID CELL LEUKODYSTROPHY.*****SUMMARY:**

This bill requires all health care institutions caring for newborn infants, within available appropriations, to test them for globoid cell leukodystrophy (GCL), unless, as allowed by law, their parents object on religious grounds. Like existing law that requires these institutions to test infants for cystic fibrosis, severe combined immunodeficiency disease, and critical congenital heart disease, the test for GCL is not part of the Department of Public Health's newborn screening program. That program, in addition to screening, directs parents of identified infants to counseling and treatment.

Under the bill, health care institutions must begin testing infants for GCL no later than six months after the federal Department of Health and Human Services' Discretionary Advisory Committee on Heritable Disorders in Newborns and Children includes the disease in its uniform screening panel. (It is not known when this will occur.)

The bill also requires the public health commissioner, within available appropriations, to establish a public education program to inform pregnant women and those who may become pregnant about GCL. The program must include information on the incidence, diagnosis, and treatment of the disease as well as associated birth defects.

The commissioner must make this information available to (1) licensed child day care centers and group day care homes, (2) licensed health care providers who serve pregnant women and infants, (3)

school nurses and others providing health education in schools, and (4) organizations providing services to children in a group setting. Additionally, health care institutions must provide the department's information on associated birth defects and treatment methods to parents of infants they screen for GCL.

EFFECTIVE DATE: July 1, 2015 except that the public education program provision takes effect January 1, 2016.

BACKGROUND

GCL

GCL, also known as Krabbe disease, is an inherited degenerative nervous system disorder. Among other things, it causes developmental delays, muscle weakness, deafness, and blindness. There is no cure for the disease, which is usually fatal before age two.

Related Bill

HB 5525, favorably reported by the Public Health Committee, requires health care institutions to test newborns who fail a required hearing screening for cytomegalovirus.

COMMITTEE ACTION

Public Health Committee

Joint Favorable

Yea 26 Nay 0 (03/23/2015)