



Senate

General Assembly

File No. 531

January Session, 2011

Senate Bill No. 543

Senate, April 14, 2011

The Committee on Public Health reported through SEN. GERRATANA of the 6th Dist., Chairperson of the Committee on the part of the Senate, that the bill ought to pass.

AN ACT PROVIDING NEWBORN SCREENING FOR SEVERE COMBINED IMMUNODEFICIENCY DISEASE.

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 Section 19a-55 of the general statutes is repealed and the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, 2011*):

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 shall adopt regulations, in accordance with
 23 chapter 54, to implement the provisions of this section.] The
 24 Commissioner of Public Health shall publish a list of all the abnormal
 25 conditions for which the department screens newborns under the
 26 newborn screening program, which shall include screening for amino
 27 acid disorders, organic acid disorders and fatty acid oxidation
 28 disorders, including, but not limited to, long-chain 3-hydroxyacyl CoA
 29 dehydrogenase (L-CHAD) and medium-chain acyl-CoA
 30 dehydrogenase (MCAD).

31 (b) In addition to the testing requirements prescribed in subsection
 32 (a) of this section, the administrative officer or other person in charge
 33 of each institution caring for newborn infants shall cause to have
 34 administered to every such infant in its care a screening test for cystic
 35 fibrosis and a screening test for severe combined immunodeficiency
 36 disease. Such screening [test] tests shall be administered as soon after
 37 birth as is medically appropriate.

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

This act shall take effect as follows and shall amend the following sections:		
Section 1	October 1, 2011	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 12 \$	FY 13 \$
Public Health, Dept.	GF - Cost	190,068	190,068
State Comptroller - Fringe Benefits ¹	GF - Cost	28,528	28,528
UConn Health Ctr.	GF - Cost	up to 3,117	up to 3,117

Note: GF=General Fund

Municipal Impact: None

Explanation

The bill, which requires all health care institutions caring for newborn infants to test them for severe immunodeficiency disease, results in a total cost to the state of \$221,713 in FY 12 and FY 13. The \$190,068 cost to the Department of Public Health supports two chemists needed to complete the new screening on approximately 42,000 newborns each year, and testing supplies. Fringe benefit costs for these positions would be \$28,528 in FY 12 and FY 13.

The John Dempsey Hospital at the University of Connecticut Health Center will incur a per test cost of \$4.55. Based on the number of births at Dempsey Hospital in FY 10 (685), this would result in an additional annual cost of \$3,117. It is likely, however, that a portion of these costs could be reimbursed through charges to the patients or insurance carriers.

It should be noted that the current newborn screening fee charged

¹ The fringe benefit costs for most state employees are budgeted centrally in accounts administered by the Comptroller. The estimated non-pension fringe benefit cost associated with personnel changes is 23.76% of payroll in FY 12 and FY 13. In addition, there could be an impact to potential liability for the applicable state pension funds.

to birthing hospitals is \$56 per newborn. Should the Commissioner of Public Health exercise her authority under CGS Sec. 19a-55a and increase this fee by, for example, \$5 to \$61, a General Fund revenue gain of \$221,713 would result, which would cover the increased cost to the state.

Approximately \$1.7 million in newborn screening fee revenue was collected in FY 10².

The Out Years

The annualized ongoing fiscal impact identified above would continue into the future subject to inflation. Pension-related costs for the identified personnel changes will be recognized in the state's annual required pension contribution as of FY 14.

² Per CGS Sec. 19a-55a, \$500,000 from these receipts is made available to DPH to pay for expenses incurred to perform the testing. Sec. 23 of HB 6380 (the Governor's budget bill) would increase this transfer of funding from the newborn screening fee receipts to DPH from \$500,000 to \$900,00 to accommodate increased testing costs.

OLR Bill Analysis**SB 543*****AN ACT PROVIDING NEWBORN SCREENING FOR SEVERE COMBINED IMMUNODEFICIENCY DISEASE.*****SUMMARY:**

This bill requires all health care institutions caring for newborn infants to test them for severe combined immunodeficiency disease (SCID), unless, as allowed by law, their parents object on religious grounds. It requires the testing to be done as soon as is medically appropriate. Like the current law that requires these institutions to test newborn infants for cystic fibrosis, the test for SCID 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.

It also requires the public health commissioner to adopt regulations to implement the testing.

EFFECTIVE DATE: October 1, 2011

BACKGROUND***Severe Combined Immunodeficiency Disease (SCID)***

SCID is a group of rare, sometimes fatal, congenital disorders characterized by little or no immune response. A person with this disease has a defect in the specialized white blood cells that defend the body from infection by viruses, bacteria, and fungi. Because the immune system does not function properly, a person with SCID is susceptible to recurrent infections such as pneumonia, meningitis, and chicken pox, and can die within the first year of life.

COMMITTEE ACTION

Public Health Committee

Joint Favorable

Yea 28 Nay 0 (03/30/2011)