



House of Representatives

General Assembly

File No. 20

January Session, 2009

House Bill No. 6263

House of Representatives, February 26, 2009

The Committee on Public Health reported through REP. RITTER of the 38th Dist., Chairperson of the Committee on the part of the House, that the bill ought to pass.

AN ACT REQUIRING THE ADMINISTRATION OF A SCREENING TEST FOR CYSTIC FIBROSIS TO NEWBORN INFANTS.

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 Section 19a-55 of the general statutes is repealed and the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, 2009*):

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 twenty-
 22 eight dollars. The commissioner shall adopt regulations, in accordance
 23 with 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. Such screening test shall be administered as soon after birth as
 36 is medically appropriate.

37 [(b)] (c) The provisions of this section shall not apply to any infant
 38 whose parents object to the test or treatment as being in conflict with
 39 their religious tenets and practice.

This act shall take effect as follows and shall amend the following sections:		
Section 1	October 1, 2009	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 10 \$	FY 11 \$
UConn Health Ctr.	SF - Revenue Gain	See Below	See Below

Note: SF=Special Fund (Non-appropriated)

Municipal Impact: None

Explanation

A revenue gain to the University of Connecticut's Health Center would result to the extent that it would bill additional patients for cystic fibrosis (CF) testing.

The Out Years

The annualized ongoing fiscal impact identified above would continue into the future subject to the number of CF screens.

OLR Bill Analysis**HB 6263*****AN ACT REQUIRING THE ADMINISTRATION OF A SCREENING TEST FOR CYSTIC FIBROSIS TO NEWBORN INFANTS.*****SUMMARY:**

This bill requires all health care institutions caring for newborn infants to test them for cystic fibrosis, unless, as allowed by law, their parents object on religious grounds. It requires the testing to be done as soon as is medically appropriate.

Under the bill, the cystic fibrosis test is in addition to, but separate from, the Public Health Department's newborn screening program for genetic diseases and metabolic disorders. That program, in addition to the initial screening test, directs parents of identified infants to appropriate counseling and treatment.

EFFECTIVE DATE: October 1, 2009

BACKGROUND***Cystic Fibrosis***

Cystic fibrosis is an inherited disorder that occurs in one in every 3,500 live births. It causes the body to produce abnormally thick secretions that clog the lungs, causing infections; obstruct the pancreas, preventing enzymes from breaking down food in the intestines; and block the bile duct, leading to liver damage. Treatment can include digestive enzyme replacement, antibiotics, and careful monitoring.

Most Connecticut birthing hospitals currently offer newborn cystic fibrosis screening on a voluntary basis. John Dempsey and Yale-New Haven hospitals conduct the actual testing.

COMMITTEE ACTION

Public Health Committee

Joint Favorable

Yea 29 Nay 1 (02/18/2009)