



# Senate

General Assembly

**File No. 95**

February Session, 2006

Senate Bill No. 162

*Senate, March 23, 2006*

The Committee on Public Health reported through SEN. MURPHY of the 16th Dist., Chairperson of the Committee on the part of the Senate, that the bill ought to pass.

***AN ACT REQUIRING NEWBORN INFANT HEALTH SCREENING FOR CYSTIC FIBROSIS.***

Be it enacted by the Senate and House of Representatives in General Assembly convened:

1 Section 1. Section 19a-55 of the 2006 supplement to the general  
2 statutes is repealed and the following is substituted in lieu thereof  
3 (*Effective October 1, 2006*):

4 (a) The administrative officer or other person in charge of each  
5 institution caring for newborn infants shall cause to have administered  
6 to every such infant in its care an HIV-related test, as defined in section  
7 19a-581, a test for phenylketonuria and other metabolic diseases, cystic  
8 fibrosis, hypothyroidism, galactosemia, sickle cell disease, maple syrup  
9 urine disease, homocystinuria, biotinidase deficiency, congenital  
10 adrenal hyperplasia 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 section shall be set at a  
 23 minimum of twenty-eight dollars. The commissioner shall adopt  
 24 regulations, in accordance with chapter 54, to implement the  
 25 provisions of this section. The Commissioner of Public Health shall  
 26 publish a list of all the abnormal conditions for which the department  
 27 screens newborns under the newborn screening program, which shall  
 28 include screening for amino acid disorders, organic acid disorders and  
 29 fatty acid oxidation disorders, including, but not limited to, long-chain  
 30 3-hydroxyacyl CoA dehydrogenase (L-CHAD) and medium-chain  
 31 acyl-CoA dehydrogenase (MCAD).

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

This act shall take effect as follows and shall amend the following sections:		
Section 1	October 1, 2006	19a-55

**PH**            *Joint Favorable*

The following fiscal impact statement and bill analysis are prepared for the benefit of members of the General Assembly, solely for the purpose of information, summarization, and explanation, and do not represent the intent of the General Assembly or either House thereof for any purpose:

### **OFA Fiscal Note**

#### **State Impact:**

<b>Agency Affected</b>	<b>Fund-Effect</b>	<b>FY 07 \$</b>	<b>FY 08 \$</b>
Public Health, Dept.	GF - Cost	346,800 - 513,400	348,700 - 548,700
Public Health, Dept.	GF - Revenue Gain	Potential	Potential
UConn Health Ctr.	SF - Savings	Potential	Potential
UConn Health Ctr.	SF - Revenue Change	Uncertain	Uncertain
Social Services, Dept.	GF - Savings	Potential	Potential
Comptroller Misc. Accounts (Fringe Benefits)	GF - Cost	35,225	103,900
Comptroller Misc. Accounts (Fringe Benefits)	Various - Cost	None	Minimal

Note: GF=General Fund; SF=Special Fund (Non-appropriated)

#### **Municipal Impact:**

<b>Municipalities</b>	<b>Effect</b>	<b>FY 07 \$</b>	<b>FY 08 \$</b>
Various Municipalities	Cost	Potential Minimal	Potential Minimal
Various Municipalities	Savings	Potential	Potential

### **Explanation**

Passage of this bill will result in a significant cost and a potential revenue gain to the Department of Public Health (DPH), and a potential savings and uncertain revenue impact to the University of Connecticut Health Center (UCHC). It could also affect state and municipally funded health insurance programs. Specific impacts are as follows:

#### **Department of Public Health**

The state will incur an FY 07 cost of approximately \$346,800 to initiate DPH screening of approximately 44,000 newborns for cystic fibrosis annually and ensure tracking and follow-up services for

families of infants identified with this inherited disorder. An estimated 2,200 newborns each year will have presumptive positive screens, requiring notification and follow-up.

The State Laboratory will incur FY 07 costs of \$205,300. This reflects the partial year salary of one Chemist position (at an annual salary of \$48,900) and costs of related laboratory supplies (chemical reagents, testing kits) of \$160,500. The Office of the State Comptroller would incur FY 07 fringe benefits costs of \$10,575<sup>1</sup>.

Additional FY 07 costs of \$116,500 will be incurred to support the partial year salaries of one Nurse Consultant (at an annual salary of \$70,700) and one Health Program Associate (at an annual salary of \$54,400) assigned to the Newborn Screening program. These staff will be required to perform follow-up activities involving families of newborns with positive screens. Also included in this amount are other expenses costs of \$10,000 for educational materials and \$2,000 in one-time equipment costs for computers. \$24,650 in additional FY 07 fringe benefits costs associated with the two positions will result.

Finally, \$25,000 in one-time data processing charges will also be incurred to modify the agency's newborn screening computer tracking system.

In FY 08 and subsequent fiscal years, an ongoing cost of approximately \$348,700 will be incurred to support the continuing costs of the three employees as well as recurring laboratory supply needs and other expenses. Fringe benefits costs of \$103,900 would also be incurred.

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<sup>1</sup> The fringe benefit costs for state employees are budgeted centrally in the Miscellaneous Accounts administered by the Comptroller. The estimated first year fringe benefit rate as a percentage of payroll is 23.6%, effective July 1, 2005. The first year fringe benefit costs for new positions do not include pension costs. The state's pension contribution is based upon the prior year's certification by the actuary for the State Employees Retirement System (SERS). The SERS 2005-06 fringe benefit rate is 34.7%, which when combined with the non pension fringe benefit rate would total 58.3%.

It is uncertain at this time whether any offsetting revenue will be generated due to passage of this bill. The DPH is currently authorized to collect a fee of at least \$28 per child from hospitals submitting samples for newborn testing. The exact fee is set at the discretion of the commissioner. If the agency elects to increase the fee to cover the costs of cystic fibrosis testing, a corresponding General Fund revenue gain, which may be significant in magnitude, will occur.

It should be noted that confirmation testing and final diagnosis of these disorders, as well as ensuing family counseling and treatment, will likely occur at one of two genetic disease treatment centers in Connecticut (Yale-New Haven Hospital, Connecticut Children's Medical Center). While the bill does not explicitly mandate support for these activities, the Department of Public Health has historically provided funding to support their operation. Enhancing this support on behalf of families with children identified pursuant to the bill to maintain par with that provided for the other disorders for which newborns are presently screened would result in an additional annualized cost of \$200,000 to the state (\$166,667 in FY 07).

#### **University of Connecticut Health Center**

Presently cystic fibrosis testing is performed at the UCHC and Yale University's School of Medicine on a voluntary basis. The UCHC performs between 22,000 – 23,000 screens annually. This testing would be assumed in whole by the DPH's State Laboratory, thus resulting in potential savings for the Health Center. A corresponding revenue loss to the UCHC Clinical Services Fund would be expected to the extent that it would cease to bill patients for this service.

It should be noted that the number of births at Dempsey Hospital is relatively low (approximately 600 annually). Consequently, it is not anticipated that the UCHC will experience a significant fiscal impact from any resulting increase in the State Laboratory fee - any additional costs would likely be partially recouped via patient billings.

The UCHC may experience a workload increase and revenue gain

to the extent that it performs additional confirmation tests and bills patients for the same.

### **Public and Municipal Health Insurance**

The expanded testing program may enhance the early identification and treatment of certain children, and thus reduce the frequency of some medical complications. To the extent that any resulting health care savings are passed on to the state through future contracts negotiated for Medicaid managed care services, a future indeterminate savings to the Department of Social Services will result. Any such savings would be partially offset by reduced federal financial participation. A potential savings may result for municipal employee health insurance plans should health care costs be reduced due to enhanced early identification and treatment.

The Office of the State Comptroller has indicated that there would be a minimal cost from the cystic fibrosis screening. It is anticipated that this cost would be incurred in FY 08 when the state is expected to enter into new health insurance contracts.

The bill's impact on municipal health insurance costs will vary by municipality depending on the current coverage. To the extent that cystic fibrosis screening is not covered under a municipality's employee health insurance policy, there would be increased municipal costs to provide it that are anticipated to be minimal.

### ***The Out Years***

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

**OLR Bill Analysis  
SB 162*****AN ACT REQUIRING NEWBORN INFANT HEALTH SCREENING  
FOR CYSTIC FIBROSIS.*****SUMMARY:**

This bill requires hospitals to test all newborns for cystic fibrosis unless, as allowed by law, their parents object on religious grounds. It adds cystic fibrosis to the other diseases and metabolic disorders included in the Department of Public Health's newborn screening program. This program directs families of identified infants to appropriate treatment programs.

EFFECTIVE DATE: October 1, 2006

**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.

Yale-New Haven and John Dempsey hospitals test for cystic fibrosis on a voluntary basis. Yale tests about 6,000 babies annually (with a 5% positive screening rate) and UConn about 24,000 (4% positive screen).

**COMMITTEE ACTION**

Public Health Committee

Joint Favorable

Yea 26 Nay 0 (03/10/2006)

