



Senate

General Assembly

February Session, 2008

File No. 426

Senate Bill No. 569

Senate, April 3, 2008

The Committee on Public Health reported through SEN. HANDLEY of the 4th Dist., Chairperson of the Committee on the part of the Senate, that the bill ought to pass.

AN ACT REQUIRING NEW 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 Section 19a-55 of the general statutes is repealed and the
2 following is substituted in lieu thereof (*Effective October 1, 2008*):

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, cystic
7 fibrosis, hypothyroidism, galactosemia, sickle cell disease, maple syrup
8 urine disease, homocystinuria, biotinidase deficiency, congenital
9 adrenal hyperplasia and such other tests for inborn errors of
10 metabolism as shall be prescribed by the Department of Public Health.
11 The tests shall be administered as soon after birth as is medically
12 appropriate. If the mother has had an HIV-related test pursuant to
13 section 19a-90 or 19a-593, the person responsible for testing under this
14 section may omit an HIV-related test. The Commissioner of Public

15 Health shall (1) administer the newborn screening program, (2) direct
 16 persons identified through the screening program to appropriate
 17 specialty centers for treatments, consistent with any applicable
 18 confidentiality requirements, and (3) set the fees to be charged to
 19 institutions to cover all expenses of the comprehensive screening
 20 program including testing, tracking and treatment. The fees to be
 21 charged pursuant to subdivision (3) of this subsection shall be set at a
 22 minimum of twenty-eight dollars. The commissioner shall adopt
 23 regulations, in accordance with chapter 54, to implement the
 24 provisions of this section. The Commissioner of Public Health shall
 25 publish a list of all the abnormal conditions for which the department
 26 screens newborns under the newborn screening program, which shall
 27 include screening for amino acid disorders, organic acid disorders and
 28 fatty acid oxidation disorders, including, but not limited to, long-chain
 29 3-hydroxyacyl CoA dehydrogenase (L-CHAD) and medium-chain
 30 acyl-CoA dehydrogenase (MCAD).

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

This act shall take effect as follows and shall amend the following sections:		
Section 1	October 1, 2008	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 chamber thereof for any purpose:

OFA Fiscal Note

State Impact:

Agency Affected	Fund-Effect	FY 09 \$	FY 10 \$
Public Health, Dept.	GF - Cost	575,819	550,777
Public Health, Dept.	GF - Revenue Gain	Potential	Potential
UConn Health Ctr.	SF - Savings	Potential Significant	Potential Significant
UConn Health Ctr.	SF - Revenue Loss	Potential Significant	Potential Significant
Social Services, Dept.	GF - Savings	Potential	Potential
Comptroller Misc. Accounts (Fringe Benefits) ¹	GF - Cost	45,359	156,414
Comptroller Misc. Accounts (Fringe Benefits)	Various - Cost	None	Minimal

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

Municipal Impact:

Municipalities	Effect	FY 09 \$	FY 10 \$
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

¹ The fringe benefit costs for state employees are budgeted centrally in the Miscellaneous Accounts administered by the Comptroller. The first year fringe benefit costs for new positions do not include pension costs. The estimated first year fringe benefit rate as a percentage of payroll is 25.36%. 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 fringe benefit rate is 33.27%, which when combined with the rate for non-pension fringe benefits totals 58.63%.

as follows:

Department of Public Health

The state will incur an FY 09 cost of \$621,178 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.

DPH costs reflect partial year support of one Chemist 2 (at an annual salary of \$53,348), one Laboratory Research Specialist (at an annual salary of \$80,344), related laboratory expenses (chemical reagents, testing kits, other expenses) of \$223,187, and one-time equipment purchases costing \$160,540 (laboratory instrumentation, computers). The Office of the State Comptroller (OSC) would incur FY 09 fringe benefit costs of \$31,296.

Additional FY 09 costs of \$79,775 will be incurred to reflect the partial year salaries of one Nurse Consultant (at an annual salary of \$77,268) and one Health Program Associate (at an annual salary of \$55,821) assigned to the Newborn Screening program. These staff will be required to perform follow-up activities with families of newborns with positive screens. Also included in this amount are other expenses of \$1,690; \$10,000 for educational materials; and \$1,540 in one-time equipment costs for computers. FY 09 fringe benefit costs associated with these positions would be \$14,063.

In FY 10, a DPH cost of \$550,777 will be incurred to support the annualized salaries of the four employees, as well as recurring laboratory supply needs and other expenses. The OSC would incur fringe benefit costs of \$156,414.

It is uncertain at this time whether any offsetting revenues will be generated due to enactment of this bill. The DPH is 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 also be noted that the above estimate is based upon the assumption that universal testing could not be initiated earlier than 2/1/09. This is due to the need to procure new instrumentation, train staff in its use, and validate clinical testing procedures (a federal requirement) prior to the implementation of the screening program.

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 about 24,000 screens annually. This testing would be assumed in whole by the State Laboratory, thus resulting in potential savings for the Health Center. A corresponding revenue loss to the UCHC's 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 10 based on the bill's effective date.

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 569*****AN ACT REQUIRING NEW INFANT HEALTH SCREENING FOR CYSTIC FIBROSIS.*****SUMMARY:**

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

EFFECTIVE DATE: October 1, 2008

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 birthing hospitals in Connecticut currently offer newborn cystic fibrosis screening on a voluntary basis. John Dempsey and Yale-New Haven hospitals conduct the tests. Dempsey annually tests about 24,000 babies and Yale tests about 6,000. Between 40,000 and 45,000 babies are born annually in the state.

COMMITTEE ACTION

Public Health Committee

Joint Favorable

Yea 28 Nay 0 (03/14/2008)