



Senate

General Assembly

January Session, 2001

File No. 299

Senate Bill No. 494

Senate, April 17, 2001

The Committee on Public Health reported through SEN. HARP of the 10th Dist., Chairperson of the Committee on the part of the Senate, that the bill ought to pass.

AN ACT CONCERNING THE SCREENING OF NEWBORNS FOR L-CHAD AND SIMILAR PROTEIN DEFICIENCIES.

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

1 Section 19a-55 of the general statutes is repealed and the following
2 is substituted in lieu thereof:

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, hypothyroidism, galactosemia,
7 sickle cell disease, maple syrup urine disease, homocystinuria,
8 biotinidase deficiency, congenital adrenal hyperplasia, l-chad (long-
9 chain 3-hydroxyacyl CoA dehydrogenase) deficiency and similar
10 protein deficiencies 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 commissioner
22 shall adopt regulations specifying the abnormal conditions to be tested
23 for and the manner of recording and reporting results.

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

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: Cost, Potential Indeterminate Revenue Gain, Potential Indeterminate Savings

Affected Agencies: Departments of Public Health, Social Services; Dempsey Hospital (University of Connecticut Health Center)

Municipal Impact: Potential Indeterminate Savings

Explanation

State Impact:

The state will incur an FY 02 cost of approximately \$621,900 to initiate screening of newborns for L-chad deficiency and similar protein deficiencies, and perform tracking and follow-up services for families with infants identified with various genetic disorders.

In order to process tests for disorders specified in the bill, the Connecticut State Laboratory will have to purchase two tandem mass spectrometers, at a total cost of approximately \$450,000. In the course of using this equipment, positive results will be indicated for up to twenty-four separate genetic disorders, an increase of sixteen over the eight screens now performed. As a result, an estimated 200 additional newborns each year will have positive test results requiring notification and follow-up.

Other laboratory costs will include \$38,500 to support the salary of one Chemist (at an annual salary of \$40,555), \$15,115 for associated fringe benefits, and \$12,000 in related laboratory supplies.

Additional FY 02 costs of \$47,600 will be incurred to support the half-year salaries of one Nurse Consultant (at an annual salary of \$64,340) and one Secretary (at an annual salary of \$36,050) required to engage in follow-up activities involving families having newborns with positive screens. A total of \$18,688 in associated fringe benefits costs will result. Finally, \$40,000 in one-time data processing charges will also be incurred in the course of modifying the agency's computer tracking system.

In FY 03 and subsequent fiscal years, an ongoing cost of approximately \$282,600 will result as one-time equipment and data processing costs will not recur. FY 03 costs include the salary of one Health Program Associate (at \$53,400) hired in the second year (as well as fringe benefit costs of \$20,965) to meet ongoing tracking and follow-up obligations.

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 having disorders identified pursuant to the bill to maintain par with that provided for the eight genetic disorders for which newborns are presently screened, would result in an additional \$300,000 annually in increased state costs.

It is uncertain at this time whether any offsetting revenue will be generated due to passage of this bill. The DPH currently collects a fee of \$18 per child from hospitals submitting samples for newborn

testing. This fee is set at the discretion of the commissioner and has remained constant for many years. If the agency elects to increase the fee to cover the costs of the tests proposed in the bill, a corresponding revenue gain will occur.

It should be noted that the number of births at Dempsey Hospital is relatively low (approximately 600 annually). The majority of these involve high-risk pregnancies where similar testing has already been performed. Consequently, it is not anticipated that the University of Connecticut Health Center will experience any significant fiscal impact should the DPH fee be increased.

The bill may enhance the early identification and treatment of affected mothers and children, and thus reduce the frequency of some medical complications commonly associated with genetic disorders. 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.

Municipal Impact:

A potential savings may result for municipal employee health insurance plans should health care costs be reduced due to enhanced early identification and treatment.

OLR Bill Analysis

SB 494

AN ACT CONCERNING THE SCREENING OF NEWBORNS FOR L-CHAD AND SIMILAR PROTEIN DEFICIENCIES.**SUMMARY:**

This bill adds L-chad and similar protein deficiencies (such as M-cad, S-cad, and S-chad) to the list of tests that hospitals and other institutions must administer to newborns. As under current law for the other tests, the L-chad and other protein deficiency tests will not be performed if the parents object on religious grounds.

L-chad is a genetic deficiency that results in an inability to break down fatty acids as a usable energy source. It can result in dangerously low blood sugar levels, poor muscle tone, and heart problems. It can also cause medical complications in the pregnant mother, including liver failure.

EFFECTIVE DATE: October 1, 2001

COMMITTEE ACTION

Public Health Committee

Joint Favorable Report

Yea 24 Nay 0