SENATE BILL REPORT
SB 5491

As Reported By Senate Committee On:
Health & Long-Term Care, February 28, 2005

Title: An act relating to describing when the department of health may collect a fee for infant screening services.

Brief Description: Describing when the department of health may collect a fee for infant screening services.

Sponsors: Senators Poulsen, Benson, Kastama and Deccio; by request of Department of Health.

Brief History:
Committee Activity: Health & Long-Term Care: 2/10/05, 2/28/05 [DPS].

SENATE COMMITTEE ON HEALTH & LONG-TERM CARE

Majority Report: That Substitute Senate Bill No. 5491 be substituted therefor, and the substitute bill do pass.
Signed by Senators Keiser, Chair; Thibaudeau, Vice Chair; Benson, Brandland, Franklin, Johnson, Kastama, Kline, Parlette and Poulsen.

Staff: Sharon Swanson (786-7447)

Background: All newborns infants born in the State of Washington are screened for several inherited genetic disorders before they are discharged from the hospital. The screening is waived only if there is a parental objection for religious reasons. The Department of Health assesses a one-time charge for the screening which is added to the bill for maternity services. The current fee is $60.90

Initially, the newborn screening was done to detect four congenital diseases: phenylketonuria (PKU), congenital hypothyroidsm, congenital adrenal hyperplasia, and hemoglobin. In October, 2003, the Board of Health added five additional diseases to the screening regime: biotinidase deficiency, galactosemia, homocystinuria, maple syrup urine disease (MSUD), and medium chain acyl co-A dehydrogenase (MCAD) deficiency.

The newborn screening fee does not cover follow-up treatment services for children. Diagnostic and treatment care is funded through many sources including government and private insurance, federal grants and self-pay. A $3.50 fee collected at the same time as the screening charge helps subsidize specialty care clinics for the disorders.

Currently, the funds raised for treatment from the specialty clinic fee can be allocated only for the treatment of the first four congenital diseases in the screening regime, which are listed in statute.

Summary of Substitute Bill: The use of funds from the speciality clinic fee are allocated to treat phenylketonuria (PKU), hemoglobin diseases, congenital adrenal hyperplasia, congenital hypothyrodism, and five additional disorders.

The Department of Health is required to conduct a study into the funding and collection mechanisms for the specialty clinics. The study must be presented to the legislature by December 1, 2006.

No changes to the specialty clinic fee may take place until April 1, 2006.

Substitute Bill Compared to Original Bill: Adds requirement that Department of Health study the funding and collection mechanisms for the specialty clinics. Does not allow any changes to the specialty clinic fee until April 1, 2006.

Appropriation: None.

Fiscal Note: Not requested.

Committee/Commission/Task Force Created: No.

Effective Date: Ninety days after adjournment of session in which bill is passed.

Testimony For: The University of Washington has one of the only PKU speciality clinic's in the northwest. The clinic not only treats children effected with metabolic disorders but also trains their families on how to care for the children at home. Social workers, doctors, and counselors are all part of the process to help families. The cost of treating children with genetic or metabolic disorders is costly but in the long run, the state saves triple that amount from early detection and prevention.

Testimony Against: The speciality fee in question is collected by hospitals. The hospitals are burdened with getting reimbursement money from medicaid or contracting with insurers to get paid. This is very cumbersome for hospitals. The issue is not treating children, there is agreement that the work the clinics do is invaluable but the issue is how speciality clinics are funded. The hospitals do not support the fact that this legislation puts them in the position of being a bill collector for a speciality clinic.

Who Testified: PRO: Jennifer Tebladi, Department of Health; Angela Fo, Biochemical Genetics Clinic; Marc Mora, Ella Mora, Emily Mora, Parents and Child living with PKU; Sean Corry, Self Advocate; Cherish Hart, March of Dimes.

CON: Lisa Thatcher, Washington State Hospitals Association; Rick Wickman, Premera.