

ACT 259

H.B. NO. 3493

A Bill for an Act Relating to Newborn Metabolic Screening.

Be It Enacted by the Legislature of the State of Hawaii:

SECTION 1. Section 321-291, Hawaii Revised Statutes, is amended to read as follows:

“[[§321-291]] Tests for phenylketonuria, hypothyroidism, and other metabolic diseases. (a) The department of health may specify diseases to be screened for in newborn infants and methods to be employed[,] to best prevent mortality and morbidity within the population of the State.

(b) The person in charge of each institution caring for newborn infants and the responsible physician attending the birth of a newborn or the person assisting the birth of a child not attended by a physician, shall ensure that every infant in the person’s care be tested for phenylketonuria, hypothyroidism, and any other disease that may be specified by the department of health; provided that this section shall not apply if the parents, [guardian,] guardians, or other [person] persons having custody or control of the child object thereto on the grounds that the tests conflict with their religious tenets and beliefs and written objection is made a part of the infant’s medical record.

(c) The department of health shall adopt rules pursuant to chapter 91, necessary for the purposes of this section, including, but not limited to:

- (1) Administration of newborn screening tests;
- (2) Quality and cost control of screening tests;
- (3) [Keeping] Retention of records and related data;
- (4) Reporting of positive test results;
- (5) Guidelines for care, treatment, and follow up of infants with positive test results;
- (6) Informing parents about the purposes of these tests; and
- (7) Maintaining the confidentiality of affected families.

(d) There is created in the treasury of the State the newborn metabolic screening special fund. All moneys for newborn metabolic screening services collected under this chapter shall be deposited in the newborn metabolic screening

special fund to be used for the payment of its lawful operating expenditures, including but not limited to laboratory testing, follow-up testing, educational materials, continuing education, quality assurance, equipment, and indirect costs.

(e) The director shall submit an annual report to the legislature twenty days prior to the convening of each regular session, identifying all fund balances, transfers, and expenditures made from the newborn metabolic screening special fund, and the purposes for each expenditure.”

SECTION 2. From July 1, 1996 to June 30, 1997, the department shall charge a fee of \$4.00 to birthing facilities for each newborn screening kit. This money shall be deposited into the special fund, to cover the costs of the newborn screening program. During this period, the department shall not be responsible for the costs of laboratory and follow-up testing.

SECTION 3. The department shall convene a panel no later than July 1, 1996, to develop a plan for providing newborn screening services to the community. The plan shall address the number of screening tests to be performed, the feasibility of using a centralized laboratory, and newborn screening fees. The panel shall consist of but not be limited to health care providers, health care insurers, laboratories, and other appropriate parties from the medical community. The panel shall submit a plan to the department no later than twenty days prior to the convening of the regular session of 1997.

SECTION 4. The department shall not adopt rules to increase the number of newborn screening tests until the plan is completed.

SECTION 5. Statutory material to be repealed is bracketed. New statutory material is underscored.

SECTION 6. This Act shall take effect upon its approval; provided that section 2 shall take effect on July 1, 1996, and shall be repealed on June 30, 1997.

(Approved June 19, 1996.)¹

Note

1. This Act was approved on June 19, 1996, which is after the approval date (June 18, 1996) of Acts 266 through 286 and Act 288.