

## SENATE BILL No. 14

AN ACT concerning the department of health and environment; relating to education and screening for congenital hypothyroidism, galactosemia, phenylketonuria and other genetic diseases and disorders; creating the Kansas newborn screening fund; amending K.S.A. 2011 Supp. 65-180, as amended by section 39 of 2012 Substitute for Senate Bill No. 397 and repealing the existing section.

*Be it enacted by the Legislature of the State of Kansas:*

Section 1. K.S.A. 2011 Supp. 65-180, as amended by section 39 of 2012 Substitute for Senate Bill No. 397, is hereby amended to read as follows: 65-180. The secretary of health and environment shall:

(a) Institute and carry on an intensive educational program among physicians, hospitals, public health nurses and the public concerning congenital hypothyroidism, galactosemia, phenylketonuria and other genetic diseases detectable with the same specimen. This educational program shall include information about the nature of such conditions and examinations for the detection thereof in early infancy in order that measures may be taken to prevent intellectual disability or morbidity resulting from such conditions.

(b) Provide recognized screening tests for phenylketonuria, galactosemia, hypothyroidism and such other diseases as may be appropriately detected with the same specimen. The initial laboratory screening tests for these diseases shall be performed by the department of health and environment or its designee for all infants born in the state. Such services shall be performed without charge.

(c) Provide a follow-up program by providing test results and other information to identified physicians; locate infants with abnormal newborn screening test results; with parental consent, monitor infants to assure appropriate testing to either confirm or not confirm the disease suggested by the screening test results; with parental consent, monitor therapy and treatment for infants with confirmed diagnosis of congenital hypothyroidism, galactosemia, phenylketonuria or other genetic diseases being screened under this statute; and establish ongoing education and support activities for individuals with confirmed diagnosis of congenital hypothyroidism, galactosemia, phenylketonuria and other genetic diseases being screened under this statute and for the families of such individuals.

(d) Maintain a registry of cases including information of importance for the purpose of follow-up services to prevent intellectual disability or morbidity.

(e) Provide, within the limits of appropriations available therefor, the necessary treatment product for diagnosed cases for as long as medically indicated, when the product is not available through other state agencies. In addition to diagnosed cases under this section, diagnosed cases of maple syrup urine disease shall be included as a diagnosed case under this subsection. Where the applicable income of the person or persons who have legal responsibility for the diagnosed individual meets medicaid eligibility, such individuals' needs shall be covered under the medicaid state plan. Where the applicable income of the person or persons who have legal responsibility for the diagnosed individual is not medicaid eligible, but is below 300% of the federal poverty level established under the most recent poverty guidelines issued by the United States department of health and human services, the department of health and environment shall provide reimbursement of between 50% to 100% of the product cost in accordance with rules and regulations adopted by the secretary of health and environment. Where the applicable income of the person or persons who have legal responsibility for the diagnosed individual exceeds 300% of the federal poverty level established under the most recent poverty guidelines issued by the United States department of health and human services, the department of health and environment shall provide reimbursement of an amount not to exceed 50% of the product cost in accordance with rules and regulations adopted by the secretary of health and environment.

(f) Provide state assistance to an applicant pursuant to subsection (e) only after it has been shown that the applicant has exhausted all benefits from private third-party payers, medicare, medicaid and other government assistance programs and after consideration of the applicant's income and assets. The secretary of health and environment shall adopt rules and regulations establishing standards for determining eligibility for state assistance under this section.

(g) (1) Except for treatment products provided under subsection (e), if the medically necessary food treatment product for diagnosed cases must be purchased, the purchaser shall be reimbursed by the department of health and environment for costs incurred up to \$1,500 per year per diagnosed child age 18 or younger at 100% of the product cost upon submission of a receipt of purchase identifying the company from which the product was purchased. For a purchaser to be eligible for reimbursement under this subsection, the applicable income of the person or persons who have legal responsibility for the diagnosed child shall not exceed 300% of the poverty level established under the most recent poverty guidelines issued by the federal department of health and human services.

(2) As an option to reimbursement authorized under subsection (g)(1), the department of health and environment may purchase food treatment products for distribution to diagnosed children in an amount not to exceed \$1,500 per year per diagnosed child age 18 or younger. For a diagnosed child to be eligible for the distribution of food treatment products under this subsection, the applicable income of the person or persons who have legal responsibility for the diagnosed child shall not exceed 300% of the poverty level established under the most recent poverty guidelines issued by the federal department of health and human services.

(3) In addition to diagnosed cases under this section, diagnosed cases of maple syrup urine disease shall be included as a diagnosed case under this subsection ~~(g)~~.

(h) The department of health and environment shall continue to receive orders for both necessary treatment products and necessary food treatment products, purchase such products, and shall deliver the products to an address prescribed by the diagnosed individual. The department of health and environment shall bill the person or persons who have legal responsibility for the diagnosed patient for a *pro-rata* share of the total costs, in accordance with the rules and regulations adopted pursuant to this section.

(i) ~~Not later than July 1, 2008,~~ The secretary of health and environment shall adopt rules and regulations as needed to require, to the extent of available funding, newborn screening tests to screen for treatable disorders listed in the core uniform panel of newborn screening conditions recommended in the 2005 report by the American college of medical genetics entitled “Newborn Screening: Toward a Uniform Screening Panel and System” or another report determined by the department of health and environment to provide more appropriate newborn screening guidelines to protect the health and welfare of newborns for treatable disorders.

(j) In performing the duties under subsection (i), the secretary of health and environment shall appoint an advisory council to advise the department of health and environment on implementation of subsection (i).

(k) The department of health and environment shall periodically review the newborn screening program to determine the efficacy and cost effectiveness of the program and determine whether adjustments to the program are necessary to protect the health and welfare of newborns and to maximize the number of newborn screenings that may be conducted with the funding available for the screening program.

(l) *There is hereby established in the state treasury the Kansas newborn screening fund which shall be administered by the secretary of health and environment. All expenditures from the fund shall be for the newborn screening program. All expenditures from the fund shall be made in accordance with appropriation acts upon warrants of the director of accounts and reports issued pursuant to vouchers approved by the secretary of health and environment or the secretary’s designee. Each month, the director of accounts and reports shall determine the amount credited to the state general fund pursuant to K.S.A. 40-3213, and amendments thereto, and shall transfer the portion of such amount that is necessary to fund the newborn screening program for the preceding month as certified by the secretary of health and environment or the secretary’s designee, to the newborn screening fund, except that such amount shall not exceed the amount to be credited to the state general fund pursuant to K.S.A. 40-3213, and amendments thereto.*

Sec. 2. K.S.A. 2011 Supp. 65-180, as amended by section 39 of 2012 Substitute for Senate Bill No. 397, is hereby repealed.

Sec. 3. This act shall take effect and be in force from and after its publication in the statute book.

I hereby certify that the above BILL originated in the SENATE, and passed that body

\_\_\_\_\_  
SENATE adopted  
Conference Committee Report \_\_\_\_\_

\_\_\_\_\_  
*President of the Senate.*

\_\_\_\_\_  
*Secretary of the Senate.*

Passed the HOUSE  
as amended \_\_\_\_\_

HOUSE adopted  
Conference Committee Report \_\_\_\_\_

\_\_\_\_\_  
*Speaker of the House.*

\_\_\_\_\_  
*Chief Clerk of the House.*

APPROVED \_\_\_\_\_

\_\_\_\_\_  
*Governor.*