Session of 2025

HOUSE BILL No. 2399

By Committee on Federal and State Affairs

Requested by Representative Bryce on behalf of Representative W. Carpenter

2-28

AN ACT concerning health and healthcare; related to newborn screening; establishing an advance universal newborn screening program; providing for the reimbursement of certain treatment services; authorizing the secretary of health and environment to specify conditions included in screenings; extending the transfer of moneys to the Kansas newborn screening fund; amending K.S.A. 65-181 and 65-183 and K.S.A. 2024 Supp. 65-180 and repealing the existing sections.

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

Section 1. K.S.A. 2024 Supp. 65-180 is hereby amended to read as follows: 65-180. *There is hereby established an advance universal newborn screening program to be administered by the secretary of health and environment.* 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~~ *conditions identified by the secretary in accordance with subsection (i)*. 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*, physical 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~~ *conditions identified by the secretary in accordance with subsection (i)*. 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;~~ *conditions identified by the secretary in accordance with subsection (i)* 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~~ *such conditions*.

(d) Maintain a registry of cases including information of importance for the purpose of follow-up services to ~~prevent intellectual~~ *support early diagnosis, treatment and services for healthy development and the prevention of* disability or morbidity.

(e) Provide, within the limits of appropriations available therefor, the necessary treatment product for diagnosed ~~cases~~ *conditions identified by the secretary in accordance with subsection (i)* for as long as medically indicated~~, when~~ *and* 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~~ *If* the applicable income of the person or persons who have legal responsibility for the diagnosed individual meets medicaid eligibility, such ~~individuals'~~ *individual's* needs shall be covered under the medicaid state plan. ~~Where~~ *If* 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~~ *If* 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 *secretary of health and environment shall adopt rules and regulations as needed to determine eligibility for reimbursement to individuals for the purchase of* 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~~ *conditions identified by the secretary in accordance with subsection (i)*.

(2) As an option to reimbursement authorized under ~~subsection (g)(1)~~ *paragraph (1)*, the department of health and environment may purchase *medically necessary* 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~~ *individuals diagnosed with conditions identified by the secretary in accordance with subsection (i)*.

~~(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.~~

(h) The department of health and environment shall continue to receive orders for both *medically* necessary treatment products and *medically* necessary food treatment products, purchase such products~~,~~ and ~~shall~~ deliver ~~the~~ *such* 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~~ *individual* for a pro-rata share of the total costs, in accordance with the rules and regulations adopted pursuant to this section.

(i) 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~~ *conditions. The secretary shall determine and identify the conditions to be included in the newborn screening tests, which may include, but not be limited to, conditions* listed in the ~~core~~ *recommended* uniform *screening* 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"~~ *issued by the United States secretary of health and human services* 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~~ *conditions*.

(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 ~~that~~*, 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. On July 1 of each year, the director of accounts and reports shall determine the amount credited to the medical assistance fee fund pursuant to K.S.A. 40-3213, and amendments thereto, and shall transfer the estimated portion of such amount that is necessary to fund the newborn screening program for the ensuing fiscal year as certified by the secretary of health and environment or the secretary's designee to the Kansas newborn screening fund. Such amount shall not exceed $5,000,000 ~~in fiscal years 2024, 2025 and 2026~~.

Sec. 2. K.S.A. 65-181 is hereby amended to read as follows: 65-181. The administrative officer or other person in charge of each institution or the attending physician, caring for infants 28 days of age or younger shall have administered to every such infant or child in its or such *institution's or* physician's care, tests for ~~congenital hypothyroidism, galactosemia, phenylketonuria and other genetic diseases which may be detected with the same specimen~~ *conditions identified by the secretary of health and environment under K.S.A. 65-180(i), and amendments thereto,* in accordance with rules and regulations adopted by the secretary of health and environment.

Sec. 3. K.S.A. 65-183 is hereby amended to read as follows: 65-183. Every physician having knowledge of a case of ~~congenital hypothyroidism, galactosemia or phenylketonuria and other genetic~~

~~diseases as may be detected with tests given pursuant to this act~~ *a condition identified by the secretary of health and environment under K.S.A. 65-180(i), and amendments thereto,* in one of such physician's own patients shall report the case to the secretary of health and environment on forms provided by the secretary.

Sec. 4. K.S.A. 65-181 and 65-183 and K.S.A. 2024 Supp. 65-180 are hereby repealed.

Sec. 5. This act shall take effect and be in force from and after its publication in the Kansas register.