AN ACT concerning health and healthcare; relating to newborn screening; establishing an advance universal newborn screening program; providing for reimbursement of treatment services; authorizing the secretary of health and environment to specify conditions included in screenings; increasing transfers of money to the Kansas newborn screening fund; amending K.S.A. 65-181 and 65-183 and repealing the existing sections.

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

New Section 1. K.S.A. 65-180 through 65-183, and amendments thereto, shall be known and may be cited as the newborn screening act.

Sec. 2. K.S.A. 2022 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 included by the secretary under 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 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 included by the secretary under 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 included by the secretary under 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, such conditions 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 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 included by the secretary under subsection (i) 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 individual's 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 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 of conditions included by the secretary under subsection (i) 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 in accordance with rules and regulations adopted by the secretary of health and environment.

(2) As an option to reimbursement authorized under subsection (g) 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 with diagnosed conditions included by the secretary under 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 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 the conditions to be included in the newborn screening tests, including, but not 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" or another report recommended by the United States
secretary of health and human services as 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 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 $2,500,000 in any one fiscal year, except that such amount shall not exceed $5,000,000 in fiscal years 2022 and 2023.

Sec. 3. 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 included 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. 4. 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 included 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. 5. K.S.A. 65-181 and 65-183 and K.S.A. 2022 Supp. 65-180 are
hereby repealed.

Sec. 6. This act shall take effect and be in force from and after its
publication in the statute book.