

SENATE BILL No. 436

By Committee on Ways and Means

2-20

1 AN ACT concerning the department of health and environment; relating to
2 education and screening for congenital hypothyroidism, galactosemia,
3 phenylketonuria and other genetic diseases and disorders; creating the
4 Kansas newborn screening fund; amending K.S.A. 2011 Supp. 65-180
5 and repealing the existing section.
6

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

8 Section 1. K.S.A. 2011 Supp. 65-180 is hereby amended to read as
9 follows: 65-180. The secretary of health and environment shall:

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

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

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

35 (d) Maintain a registry of cases including information of importance
36 for the purpose of follow-up services to prevent mental retardation or

1 morbidity.

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

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

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

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

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

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

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

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

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

40 *(l) There is hereby established in the state treasury the Kansas*
41 *newborn screening fund which shall be administered by the secretary of*
42 *health and environment. All expenditures from the fund shall be for the*
43 *newborn screening program. All expenditures from the fund shall be made*

1 *in accordance with appropriation acts upon warrants of the director of*
2 *accounts and reports issued pursuant to vouchers approved by the*
3 *secretary of health and environment or the secretary's designee. Each*
4 *month, the director of accounts and reports shall determine the amount*
5 *credited to the state general fund pursuant to K.S.A. 40-3213, and*
6 *amendments thereto, and shall transfer the amount equal to the amount so*
7 *determined from the state general fund to the Kansas newborn screening*
8 *fund, except that the aggregate amount transferred for any fiscal year*
9 *shall not exceed \$3,000,000.*

10 Sec. 2. K.S.A. 2011 Supp. 65-180 is hereby repealed.

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