

SENATE BILL No. 364

By Committee on Ways and Means

2-4

1 AN ACT concerning health and healthcare; relating to newborn screening;
2 reimbursement of treatment services; authorizing the secretary of health
3 and environment to specify conditions included in screenings;
4 increasing transfers to the Kansas newborn screening fund; amending
5 K.S.A. 65-180, 65-181 and 65-183 and repealing the existing sections.

6
7 *Be it enacted by the Legislature of the State of Kansas:*

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

11 Sec. 2. K.S.A. 65-180 is hereby amended to read as follows: 65-180.

12 *There is hereby established an advance universal newborn screening*
13 *program to be administered by the secretary of health and environment.*

14 The secretary of health and environment shall:

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

23 (b) Provide recognized screening tests for ~~phenylketonuria,~~
24 ~~galactosemia, hypothyroidism and such other diseases as may be~~
25 ~~appropriately detected with the same specimen conditions included by the~~
26 ~~secretary under subsection (i).~~ The initial laboratory screening tests for
27 these diseases shall be performed by the department of health and
28 environment or its designee for all infants born in the state. Such services
29 shall be performed without charge.

30 (c) Provide a follow-up program by providing test results and other
31 information to identified physicians; locate infants with abnormal newborn
32 screening test results; with parental consent, monitor infants to assure
33 appropriate testing to either confirm or not confirm the disease suggested
34 by the screening test results; with parental consent, monitor therapy and
35 treatment for infants with confirmed diagnosis of ~~congenital~~
36 ~~hypothyroidism, galactosemia, phenylketonuria or other genetic diseases~~

1 ~~being screened under this statute~~ *conditions included by the secretary*
2 *under subsection (i); and establish ongoing education and support*
3 *activities for individuals with confirmed diagnosis of* ~~congenital~~
4 ~~hypothyroidism, galactosemia, phenylketonuria and other genetic diseases~~
5 ~~being screened under this statute~~ *such conditions* and for the families of
6 such individuals.

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

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

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

41 (g) (1) Except for treatment products provided under subsection (e), if
42 the medically necessary food treatment product for diagnosed ~~eases~~
43 *conditions included by the secretary under subsection (i)* must be

1 purchased, the purchaser shall be reimbursed by the department of health
2 and environment for costs incurred up to \$1,500 per year per diagnosed
3 child age 18 or younger at 100% of the product cost upon submission of a
4 receipt of purchase identifying the company from which the product was
5 purchased. For a purchaser to be eligible for reimbursement under this
6 subsection, the applicable income of the person or persons who have legal
7 responsibility for the diagnosed child shall not exceed 300% of the poverty
8 level established under the most recent poverty guidelines issued by the
9 federal department of health and human services *in accordance with rules
10 and regulations adopted by the secretary of health and environment.*

11 (2) As an option to reimbursement authorized under subsection (g)
12 paragraph (1), the department of health and environment may purchase
13 *medically necessary* food treatment products for distribution to diagnosed
14 children in an amount not to exceed \$1,500 per year per diagnosed child
15 age 18 or younger. For a diagnosed child to be eligible for the distribution
16 of food treatment products under this subsection, the applicable income of
17 the person or persons who have legal responsibility for the diagnosed child
18 shall not exceed 300% of the poverty level established under the most
19 recent poverty guidelines issued by the federal department of health and
20 human services *to individuals with diagnosed conditions included by the
21 secretary under subsection (i).*

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

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

33 (i) The secretary of health and environment shall adopt rules and
34 regulations as needed to require, to the extent of available funding,
35 newborn screening tests to screen for treatable ~~disorders~~ *conditions*. *The
36 secretary shall determine the conditions to be included in the newborn
37 screening tests, including, but not limited to, conditions listed in the eore
38 recommended uniform screening panel of newborn screening conditions
39 recommended in the 2005 report by the American college of medical
40 genetics entitled "Newborn Screening: Toward a Uniform Screening Panel
41 and System" or another report recommended by the United States
42 secretary of health and human services as determined by the department
43 of health and environment to provide more appropriate newborn screening*

1 guidelines to protect the health and welfare of newborns for treatable
2 ~~disorders conditions.~~

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

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

12 (l) There is hereby established in the state treasury the Kansas
13 newborn screening fund that shall be administered by the secretary of
14 health and environment. All expenditures from the fund shall be for the
15 newborn screening program. All expenditures from the fund shall be made
16 in accordance with appropriation acts upon warrants of the director of
17 accounts and reports issued pursuant to vouchers approved by the
18 secretary of health and environment or the secretary's designee. On July 1
19 of each year, the director of accounts and reports shall determine the
20 amount credited to the medical assistance fee fund pursuant to K.S.A. 40-
21 3213, and amendments thereto, and shall transfer the estimated portion of
22 such amount that is necessary to fund the newborn screening program for
23 the ensuing fiscal year as certified by the secretary of health and
24 environment or the secretary's designee to the Kansas newborn screening
25 fund, except that such amount shall not exceed ~~\$2,500,000~~ \$5,000,000 in
26 any one fiscal year.

27 Sec. 3. K.S.A. 65-181 is hereby amended to read as follows: 65-181.
28 The administrative officer or other person in charge of each institution or
29 the attending physician; caring for infants 28 days of age or younger shall
30 have administered to every such infant or child in ~~its or~~ such *institution's*
31 *or* physician's care; tests for ~~congenital hypothyroidism, galactosemia,~~
32 ~~phenylketonuria and other genetic diseases which may be detected with~~
33 ~~the same specimen~~ *conditions included by the secretary of health and*
34 *environment under K.S.A. 65-180(i), and amendments thereto,* in
35 accordance with rules and regulations adopted by the secretary of health
36 and environment.

37 Sec. 4. K.S.A. 65-183 is hereby amended to read as follows: 65-183.
38 Every physician having knowledge of a case of ~~congenital~~
39 ~~hypothyroidism, galactosemia or phenylketonuria and other genetic~~
40 ~~diseases as may be detected with tests given pursuant to this act~~ *a*
41 *condition included by the secretary of health and environment under*
42 *K.S.A. 65-180(i), and amendments thereto,* in one of such physician's own
43 patients shall report the case to the secretary of health and environment on

1 forms provided by the secretary.

2 Sec. 5. K.S.A. 65-180, 65-181 and 65-183 are hereby repealed.

3 Sec. 6. This act shall take effect and be in force from and after its

4 publication in the Kansas register.