

SENATE BILL No. 177

By Committee on Public Health and Welfare

1-25

9 AN ACT concerning the department of health and environment; relating
10 to education and screening for congenital hypothyroidism, galactose-
11 mia, phenylketonuria and other genetic diseases and disorders; assis-
12 tance for certain expenses; amending K.S.A. 2006 Supp. 65-180 and
13 repealing the existing section.
14

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

16 Section 1. K.S.A. 2006 Supp. 65-180 is hereby amended to read as
17 follows: 65-180. The secretary of health and environment shall:

18 (a) Institute and carry on an intensive educational program among
19 physicians, hospitals, public health nurses and the public concerning con-
20 genital hypothyroidism, galactosemia, phenylketonuria and other genetic
21 diseases detectable with the same specimen. This educational program
22 shall include information about the nature of such conditions and exam-
23 inations for the detection thereof in early infancy in order that measures
24 may be taken to prevent the mental retardation or morbidity resulting
25 from such conditions.

26 (b) Provide recognized screening tests for phenylketonuria, galacto-
27 semia, hypothyroidism and such other diseases as may be appropriately
28 detected with the same specimen. The initial laboratory screening tests
29 for these diseases shall be performed by the department of health and
30 environment *or its designee* for all infants born in the state. Such services
31 shall be performed ~~without charge~~ *for a fee of not more than \$30 per*
32 *newborn.*

33 (c) Provide a follow-up program by providing test results and other
34 information to identified physicians; locate infants with abnormal new-
35 born screening test results; with parental consent, monitor infants to as-
36 sure appropriate testing to either confirm or not confirm the disease sug-
37 gested by the screening test results; with parental consent, monitor
38 therapy and treatment for infants with confirmed diagnosis of congenital
39 hypothyroidism, galactosemia, phenylketonuria or other genetic diseases
40 being screened under this statute; and establish ongoing education and
41 support activities for individuals with confirmed diagnosis of congenital
42 hypothyroidism, galactosemia, phenylketonuria and other genetic dis-
43 eases being screened under this statute and for the families of such

1 individuals.

2 (d) Maintain a registry of cases including information of importance
3 for the purpose of follow-up services to prevent mental retardation or
4 morbidity.

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

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

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

1 exceed 300% of the poverty level established under the most recent pov-
2 erty guidelines issued by the federal department of health and human
3 services.

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

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

17 (h) The department of health and environment shall continue to re-
18 ceive orders for both necessary treatment products and necessary food
19 treatment products, purchase such products, and shall deliver the prod-
20 ucts to an address prescribed by the diagnosed individual. The depart-
21 ment of health and environment shall bill the person or persons who have
22 legal responsibility for the diagnosed patient for a pro-rata share of the
23 total costs, in accordance with the rules and regulations adopted pursuant
24 to this section. ~~The department of health and environment and the Kansas
25 health policy authority shall combine the purchasing resources for the
26 purpose of this subsection and shall enter into a joint contract for the
27 purchase of all products for both medicaid and nonmedicaid eligible cli-
28 ents.~~

29 (i) *Not later than July 1, 2008, the secretary of health and environ-
30 ment shall adopt rules and regulations as needed to require, to the extent
31 of available funding, newborn screening tests to screen for disorders listed
32 in the core uniform panel of newborn screening conditions recommended
33 in the 2005 report by the American college of medical genetics entitled
34 "Newborn Screening: Toward a Uniform Screening Panel and System" or
35 another report determined by the department of health and environment
36 to provide more appropriate newborn screening guidelines to protect the
37 health and welfare of newborns.*

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

42 (k) *The department of health and environment shall periodically re-
43 view the newborn screening program to determine the efficacy and cost*

1 *effectiveness of the program and determine whether adjustments to the*
2 *program are necessary to protect the health and welfare of newborns and*
3 *to maximize the number of newborn screenings that may be conducted*
4 *with the funding available for the screening program.*

5 Sec. 2. K.S.A. 2006 Supp. 65-180 is hereby repealed.

6 Sec. 3. This act shall take effect and be in force from and after its
7 publication in the Kansas register.