

HOUSE BILL No. 2971

By Committee on Appropriations

2-21

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. 65-180 and repealing the
13 existing section.
14

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

16 Section 1. K.S.A. 65-180 is hereby amended to read as follows: 65-
17 180. 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 the designee of the department*, for all infants born in
31 the state. ~~Such services shall be performed without charge.~~

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

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

4 (e) Provide, *within the limits of appropriations available therefor*, the
5 necessary treatment product for diagnosed cases for as long as medically
6 indicated, when the product is not available through other state agencies.
7 In addition to diagnosed cases under this section, diagnosed cases of ma-
8 ple syrup urine disease shall be included as a diagnosed case under this
9 subsection.

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

17 (g) (1) Except for treatment products provided under subsection (e),
18 if the medically necessary food treatment product for diagnosed cases
19 must be purchased, the purchaser shall be reimbursed by the department
20 of health and environment for costs incurred up to \$1,500 per year per
21 diagnosed child age 18 or younger at 100% of the product cost upon
22 submission of a receipt of purchase identifying the company from which
23 the product was purchased. For a purchaser to be eligible for reimburse-
24 ment under this subsection ~~(f)~~ (g)(1), the applicable income of the person
25 or persons who have legal responsibility for the diagnosed child shall not
26 exceed 300% of the poverty level established under the most recent pov-
27 erty guidelines issued by the federal department of health and human
28 services.

29 (2) As an option to reimbursement authorized under subsection ~~(f)~~
30 (g)(1), the department of health and environment may purchase food
31 treatment products for distribution to diagnosed children in an amount
32 not to exceed \$1,500 per year per diagnosed child age 18 or younger. For
33 a diagnosed child to be eligible for the distribution of food treatment
34 products under this subsection ~~(f)~~ (g)(2), the applicable income of the
35 person or persons who have legal responsibility for the diagnosed child
36 shall not exceed 300% of the poverty level established under the most
37 recent poverty guidelines issued by the federal department of health and
38 human services.

39 (3) In addition to diagnosed cases under this section, diagnosed cases
40 of maple syrup urine disease shall be included as a diagnosed case under
41 this subsection ~~(f)~~ (g).

42 (h) *Not later than July 1, 2007, the secretary of health and environ-*
43 *ment shall adopt rules and regulations as needed to require, to the extent*

1 *of available funding, newborn screening tests to screen for disorders listed*
2 *in the core uniform panel of newborn screening conditions recommended*
3 *in the 2005 report of the American College of Medical Genetics entitled*
4 *“Newborn Screening: Toward a Uniform Screening Panel and System” or*
5 *another report determined by the department of health and environment*
6 *to provide more appropriate newborn screening guidelines to protect the*
7 *health and welfare of Kansas newborns.*

8 *(i) In performing the duties of the department of health and environ-*
9 *ment under subsection (g), the secretary of health and environment shall*
10 *appoint an advisory council to advise the department of health and en-*
11 *vironment on implementation of subsection (h).*

12 *(j) The department of health and environment shall periodically re-*
13 *view the newborn screening program to determine the efficacy and cost-*
14 *effectiveness of the program and to determine whether the adjustments to*
15 *the program are necessary to protect the health and welfare of Kansas*
16 *newborns and to maximize the number of newborn screenings that may*
17 *be conducted within the funding available for the screening program.*

18 Sec. 2. K.S.A. 65-180 is hereby repealed.

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