

MINUTES OF THE HOUSE APPROPRIATIONS COMMITTEE

The meeting was called to order by Chairman Melvin Neufeld at 9:00 A.M. on March 20, 2006 in Room 514-S of the Capitol.

All members were present except:

- Representative Bonnie Huy- excused
- Representative Bill Light- excused
- Representative Shari Weber- excused
- Representative Tom Sawyer- excused

Committee staff present:

- J. G. Scott, Legislative Research Department
- Becky Krahl, Legislative Research Department
- Matt Spurgin, Legislative Research Department
- Susan Kannarr, Legislative Research Department
- Amy VanHouse, Legislative Research Department
- Jim Wilson, Revisor of Statutes
- Nikki Feuerborn, Administrative Assistant
- Shirley Jepson, Committee Secretary

Conferees appearing before the committee:

Others attending:

See attached list.

- Attachment 1      Budget Committee Report on **HB 2971**
- Attachment 2      Balloon on **HB 2971**

**Discussion and Action on HB 2971 - Department of health and environment, certain genetic diseases and disorders, education and screening, assistance.**

Representative Landwehr, Chair of the Social Services Budget Committee, presented the Budget Committee report on **HB 2971** (Attachment 1) and a balloon amendment (Attachment 2); moved for adoption of the Budget Committee Report and authorize the correction of language in the balloon, Page 2, Line 9, from "shall require" to "shall provide". The motion was seconded by Representative Henry. Motion carried.

The Budget Committee noted their concern with the provisions in the bill for newborn screening. The bill would have expanded the newborn screening from 4 tests to 29 tests. Issues which need to be addressed include:

- The bill would make the screening mandatory and did not address who would be responsible for the funding.
- Some screening might not be treatable.

The Budget Committee supports the newborn screening but felt the issue needs more time for research and discussion. It is anticipated that more information will be available by Omnibus or the issue could be referred to an interim committee for further review.

Representative Landwehr moved to move the language of **HB 2971** as amended by the Budget Committee report into **SB 579**, allow for technical corrections, recommend **SB 579** as amended favorably for passage as amended and to be reported as **House Substitute for SB 579**. The motion was seconded by Representative Bethell. Motion carried.

**Discussion and Action on SB 420 - Amendments to the Kansas payment center statute; repealing the sunset provision regarding the state being fined for lack of compliance with title IV-D.**

Representative Landwehr moved to recommend **SB 420** favorable for passage. The motion was seconded by Representative Bethell. Motion carried.

CONTINUATION SHEET

MINUTES OF THE House Appropriations Committee at 9:00 A.M. on March 20, 2006 in Room 514-S of the Capitol.

**Discussion and Action on HB 2520 - Community mental health center licensure.**

Representative Landwehr moved to recommend HB 2520 favorable for passage. The motion was seconded by Representative Ballard. Motion carried.

**Discussion and Action on HB 2762 - Adult care home administrators, grounds for licensure action, board membership.**

Representative Landwehr moved to move the language of HB 2762 as amended into SB 574, allow for technical corrections, recommend SB 574 as amended favorable for passage and report as House Substitute for SB 574. The motion was seconded by Representative Bethell. Motion carried.

**Discussion and Action on HB 2861 - Exercising the state's option to provide an exemption to disqualification for public assistance to certain drug offenders.**

Representative Landwehr moved to strip the language in SB 243, move the language of HB 2861 into SB 243, allow for technical corrections, recommend SB 243 as amended favorable for passage and report as House Substitute for SB 243. The motion was seconded by Representative Bethell.

The Budget Committee noted that the fiscal note on HB 2861 is \$380,640 State General Fund (SGF) and \$730,236 all funds.

Representative Yoder moved for a substitute motion to amend HB 2861 by striking the word "may" on Page 1, Line 31 and replace with the word "shall". The motion was seconded by Representative Landwehr. Motion carried.

Representative Landwehr renewed the motion to strip the language in SB 243, move the language of HB 2861 into SB 243, allow for technical corrections, recommend SB 243 as amended favorable for passage and report as House Substitute for SB 243. The motion was seconded by Representative Bethell. Motion carried.

The meeting was adjourned at 10:00 a.m. The next meeting of the Committee will be held at 9:00 a.m. on March 21, 2006.

  
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Melvin Neufeld, Chairman



HOUSE SOCIAL SERVICES BUDGET COMMITTEE

HB 2971

  
Representative Brenda Landwehr, Chair

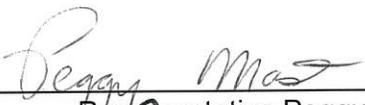
  
Representative Bob Bethell

  
Representative Barbara Ballard

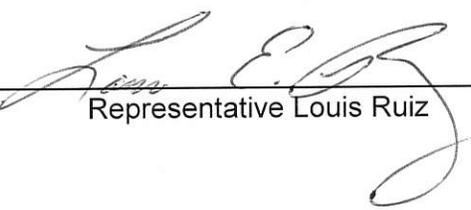
  
Representative Jerry Henry

  
Representative Willa DeCastro

Representative John Edmonds

  
Representative Peggy Mast

  
Representative Arlen Siegfried

  
Representative Louis Ruiz

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ATTACHMENT 1

## House Social Services Budget Committee

### Recommendation on House Bill 2971

The Budget Committee recommends the bill favorably for passage with the following amendments and notations:

1. Amend the bill to provide payment for the necessary treatment product for individuals diagnosed with the diseases addressed in the bill as follows:
  - a. Needs shall be covered by Medicaid for individuals meeting Medicaid eligibility;
  - b. The Department of Health and Environment shall adopt rules and regulations establishing a reimbursement program between 50 percent and 100 percent of the product cost for families not eligible for Medicaid but below 300 percent of the Federal poverty level; and
  - c. The Department of Health and Environment shall adopt rules and regulations establishing a reimbursement program not to exceed 50 percent of the product costs for families who exceed 300 percent of the Federal poverty level.
2. Amend the bill to insure that the Department of Health and Environment will continue to receive orders for both the necessary treatment product and necessary food treatment products, purchase such products, and deliver the products to an address provided by the families. The Department will bill the families in accordance to the adopted rules and regulations. The Department and the Health Policy Authority are directed to pool purchasing power and enter into a joint contract for the purchase of products for both Medicaid and non-Medicaid clients.
3. Delete changes on page 1, lines 30 - 31, and page 2, line 42 through page 3, line 17. This amendment deletes items in the bill in reference to newborn screening.
4. The Budget Committee notes that the agency will have greater flexibility through the rules and regulations process to administer this program.
5. The Budget Committee directs the agency to continue discussion with stakeholders in regard to adjustments to the newborn screening. The agency is directed to report at Omnibus on recommended adjustments to the newborn screening panel and process.

## Brief

HB 2971 would amend the law regarding infant screening to add that initial laboratory screening may be performed by a designee of the Department of Health and Environment. The bill would also delete language stating that the screening would be done without charge.

In addition, the bill would require the Secretary of Health and Environment to adopt rules and regulations as needed to require newborn screening tests to screen for disorders listed in the core uniform panel of newborn screening conditions recommended in the 2005 report of the American College of Medical Genetics. The Secretary also would be required to appoint an advisory council on the implementation of these tests.

The bill would require the Department of Health and Environment to periodically review the newborn screening program to determine the cost effectiveness of the program and whether adjustments are needed in the program.

Further, the bill would add language stating that treatment products provided by the agency would be limited to available appropriations. Language also would be included that state assistance be provided only after all other benefits from private third-party payers, Medicare, Medicaid, and other government assistance programs are exhausted. The Secretary of Health and Environment would be required to adopt rules and regulations establishing income eligibility requirements for state assistance.

## Background

HB 2971 was introduced by the House Committee on Appropriations. At the hearing held by the Social Services Budget Committee, the Department of Health and Environment Deputy Director of Health testified in favor of the bill. Also testifying in favor of the bill were the State Director of the March of Dimes, representatives of the Regional Collaborative of Heartland Genetics and the Save Babies Through Screening Foundation, and the parents and grandparents of children impacted by genetic diseases.

Speaking in opposition to portions of the bill included parents of children and an individual diagnosed with phenylketonuria. Also speaking in opposition to portions of the bill was a medical doctor specializing in the several diseases addressed in the bill.

Appearing as a neutral conferee was a pediatric dietitian with the University of Kansas Medical Center/Developmental Disabilities Center.

The fiscal note on the original bill states that the program changes in the bill would result in savings of approximately \$100,000 from the budget amount for FY 2007.

**HOUSE BILL No. 2971**

By Committee on Appropriations

2-21

Proposed amendment for consideration  
by House Committee on Appropriations

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.~~

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.

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ATTACHMENT 2

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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~~

Where the applicable income of the person or persons who have legal responsibility for the diagnosed individual meets medicaid eligibility, such individuals' 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 not medicaid eligible, but 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 require 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 require 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.

2-3

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.

(h) The department of health and environment shall continue to receive orders for both necessary treatment products and 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 for a pro-rata share of the total costs, in accordance with the rules and regulations adopted pursuant to this section. The department of health and environment and the Kansas health policy authority shall combine the purchasing resources for the purpose of this subsection and shall enter into a joint contract for the purchase of all products for both medicaid and non-medicaid eligible clients.