

MINUTES OF THE HOUSE HEALTH AND HUMAN SERVICES COMMITTEE

The meeting was called to order by Chairman Jim Morrison at 1:48 p.m. on March 8, 2004, in Room 526-S of the Capitol.

All members were present except:

Representative Brenda Landwehr- excused
Representative Tom Holland- excused
Representative Willa DeCastro- excused
Representative Joe McLeland -excused

Committee staff present:

Dr. William Wolff, Legislative Research Department
Rena Jefferies, Office of Revisor of Statutes
Gary Deeter, Secretary

Conferees appearing before the committee:

Linda Kenney, Director, Bureau for Children, Youth and Families, Kansas Department of Health and Environment
Norm Hess, Director of Program Services, March of Dimes Greater Kansas Chapter
Doug Bowman, Coordinating Council on Early Childhood Developmental Services
Chris Collins, Director of Governmental Affairs and Associate General Counsel, Kansas Medical Society

Others attending:

See Attached List.

The Committee Minutes for 3-4-04 were approved as printed.

The Vice-Chair opened the hearing on **SB 418**, a bill which creates a birth defects information system. Linda Kenney, Director, Bureau for Children, Youth and Families, Kansas Department of Health and Environment (KDHE), testified as a proponent for the bill. (Attachment 1) She said that birth defects are the leading cause of infant mortality in Kansas, contribute to long-term disability, and are the cause of 30% of admissions to pediatric hospitals, noting that surveillance is a critical component in reducing the impact of this health problem. She said such a system would link program and service needs to surveillance findings, stating that if the bill passes, KDHE will attempt to find alternative sources of funding to minimize the use of State General Funds. Answering questions, Ms. Kenney said the project provides the statutory basis needed to seek federal funds through the Center for Disease Control (CDC).

Norm Hess, Director of Program Services, March of Dimes Greater Kansas Chapter, spoke in favor of the bill, saying that a statewide birth defects information system would more effectively identify the needs for service and treatment of the 1200-1500 babies born annually in Kansas with a major birth defect, noting that birth defects are not always identified on the present vital statistics form. (Attachment 2) He said CDC funding for such systems is expected to continue and that 35 states currently receive funding through

CONTINUATION SHEET

MINUTES OF THE HOUSE HEALTH AND HUMAN SERVICES COMMITTEE at 1:48 p.m. on March 8, 2004, in Room 526-S of the Capitol.

cooperative agreements with the CDC. He said the bill contains appropriate measures to protect the confidentiality of children and families.

Doug Bowman, staff member for the Coordinating Council on Early Childhood Developmental Services, spoke as a proponent, saying that anecdotal information regarding localized regions where one kind of disability or another is found in disproportionate frequency could be verified with the system proposed by the bill. (Attachment 3)

Chris Collins, Legislative Director, Kansas Medical Society, said the Society had surveyed the language of the bill and has some concerns that, because the registry grants KDHE access to medical records, some of which might be sensitive, she suggested the Committee make certain that these records under KDHE control not be available to any other party. She said she would have an amendment available by the end of the day. (The amendment is included in the testimony as Attachment 4.)

The hearing for **SB 418** was closed.

The Vice-Chair opened the hearing on **SB 511**, which establishes a screening process for newborn infants for hearing loss.

Linda Kenney testified in favor of the bill. (Attachment 5) She said the bill came about at the direction of the Joint Committee on Administrative Rules and Regulations to amend the Newborn Hearing Screening Law (**K.S.A. 65-1,157a**) to provide statutory authority for the Secretary to carry out the screening program in the proposed newborn hearing screening rules and regulations.

The hearing on **SB 511** was closed.

Staff Bill Wolff gave a briefing on **SB 453**, which exempts educational institutions from child care facility regulations. He said the bill exempts school districts from the child-care licensure laws if they annually certify that the child-care facilities or program meets the fire and building codes, has no students under age 3, is supervised by a certificated teacher or administrator, conducts criminal background checks on all staff members, and is offered at a site owned or leased by the school district.

The meeting was adjourned at 2:12 p.m.



K A N S A S

RODERICK L. BREMBY, SECRETARY

KATHLEEN SEBELIUS, GOVERNOR

DEPARTMENT OF HEALTH AND ENVIRONMENT

Testimony on Birth Defects Information System, SB 418

to

House Health & Human Services Committee

by Linda Kenney

Director, Bureau for Children, Youth and Families
Kansas Department of Health and Environment

March 8, 2004

The Kansas Department of Health and Environment supports passage of SB 418. We believe that a birth defects registry should be a feature of the Kansas public health system. Birth defects are the leading cause of infant mortality in Kansas and the U.S. In addition, birth defects are the 5th leading cause of years of potential life lost before age 65 and contribute substantially to childhood morbidity and long-term disability. About 30% of all admissions to pediatric hospitals are because of an illness related to a birth defect. Birth defects have a significant economic impact. Costs pale in comparison to the cost of personal anguish for the family and the loss of creativity and productivity of individuals with such conditions.

The etiology of most of these conditions is not yet known, however, where an etiology has been determined, it is often possible to prevent the condition. For example, over 50% of neural tube defects are preventable with the preconception use of vitamin folic acid. Fetal alcohol syndrome may be prevented by abstaining from alcohol during pregnancy. Congenital rubella syndrome is preventable by ensuring immunization of all women. All these interventions are cost-effective.

Birth defects surveillance is a critical component in the effort to reduce the impact of this health problem. It helps to monitor occurrence of birth defects for changes in incidence or for the presence of unusual patterns that may suggest the introduction of new teratogens (agents linked with fetal deformities). It establishes a case registry for use in epidemiologic and genetic studies. In recent years there has been a trend to link program and service needs to surveillance findings. Thus, the system would provide data for health policy decisions and formulation of interventions, and evaluation of the impact of such measures. The system would also identify children who require special services and link them early on with appropriate care providers.

We commend the legislature for recognizing the importance of a birth defects information system to the State's overall public health system. If this legislation passes, KDHE will attempt to identify alternatives to SGF funding for the system and will report any funds to the Committee. Thank you for the opportunity to appear before this committee to support your legislation. I will gladly stand for questions.



Establishing a Birth Defects Information System in Kansas
Testimony on behalf of the March of Dimes
Before the House Committee on Health and Human Services
March 8, 2004

My name is Norm Hess, and I am the Director of Program Services for the March of Dimes Greater Kansas Chapter. Thank you for the opportunity to express our strong support of Senate Bill 418, to authorize the establishment of a statewide birth defects information system.

Based on national estimates by the Centers for Disease Control and Prevention (CDC), 1,200 - 1,500 babies were born in Kansas with a major birth defect in the year 2000. The CDC estimates that at least 20% - more than 50 babies - died in Kansas that year because of birth defects. Some of these conditions are diagnosable at birth and are recorded on the birth certificate. Others may not manifest symptoms for several months and may never be reported to the Kansas Department of Health and Environment (KDHE) under the current reporting system.

According to the CDC, Kansas is one of only 4 states that do not have an active reporting birth defects information system. Currently, 35 states receive funding through cooperative agreements from the CDC to plan and implement birth defects information systems. These agreements have resulted in more timely and accurate birth defects data and have led to stronger, more coordinated systems of care for children and families.

CDC funding for the purposes of establishing or enhancing state birth defects information systems is expected to continue. Passage of authorizing legislation at this time will strengthen the state's position in applying for these funds.

The reporting of health-related information to the state health authority is a long-standing public health practice, and KDHE routinely collects, stores, and processes confidential health information. SB 418 contains appropriate measures to protect the confidentiality of children and families, including a provision for parents or guardians to have identifying information about their children removed from the system.

The March of Dimes strongly supports SB 418 to benefit the families of children who are born with major birth defects in Kansas each year. Thank you for your consideration of this bill.

Norm Hess, MSA - Director of Program Services
March of Dimes Greater Kansas Chapter
816-561-0175

Attachment 2
HHS 3-8-04

TESTIMONY BEFORE HOUSE HEALTH & HUMAN SERVICES COMMITTEE - 3/8/04

Mr. Chairman and members of the committee, thank you for the opportunity to testify today. My name is Doug Bowman. I serve as staff to the Coordinating Council on Early Childhood Developmental Services. Our mission is to advise on matters pertaining to young children age birth to five years with (or at risk of) developmental delay or disability.

We are supportive of SB 418. For years, we have heard anecdotal stories of localized regions where one kind of disability or another is found in disproportionate frequency. Among the benefits of the provisions of this bill is the creation of data which would confirm (or disprove) these theories. Research of this kind would further our efforts to prevent human tragedy.

Finally, I would like to remind you of HB 2350, which passed out of this committee favorably. We still believe strongly in the activity described in HB 2350. The current SB 418 has language which encompasses HB 2350 - Section 2 (8) lines 22-23.

If for any reason SB 418 fails to become law, we encourage you to reconsider HB 2350 for amendment into another bill. Thank you for your time and attention.

Attachment 3
HHS 3-8-04



TO: House Health and Human Services Committee

FROM: Christina Collins
Director of Government Affairs

DATE: March 8, 2004

RE: Proposed amendment to SB 418 which creates a Birth Defect Registry

Chairman Morrison and Members of the Committee:

Thank you for considering my testimony before the committee today. Please accept my apology for not providing this information prior to the hearing; the attached amendment results from discussions about the bill that transpired just this morning.

The Kansas Medical Society favors the implementation of registries that allow KDHE to gather meaningful data on birth defects in Kansas and to disseminate helpful information to parents of these children.

However, this registry differs from others this body has considered in that it grants KDHE authority to request relevant medical records. The bill's current language does make the records confidential; however, the Kansas Medical Society seeks additional protections for these records that would not otherwise be in the custody of the Kansas Department of Health and Environment to ensure that they cannot be subsequently released by KDHE. While it is helpful for KDHE to access this information, these records contain confidential medical information of a highly sensitive nature. For this reason, the interested parties, including the March of Dimes and KDHE have approved the addition of the attached amendment to the bill's current language.

The proposed language is almost identical to that adopted by the Senate Judiciary Committee and the Senate as a whole to SB 466, which creates protections for medical records a physician may provide to the Division of Motor Vehicles to substantiate a report that a patient lacks the capacity to drive safely. Again, parties who may need access to these records have adequate alternative means to secure them but the highly personal nature of the records merits their continued protection after these records leave the control of the health care professional or the patient themselves.

Attachment 4
HHS 3-8-04

Again, we support the goal of creating a birth defect registry but feel these protections are important to safeguard the privacy and dignity of the children who suffer from these tragic conditions. I am pleased to respond to any questions the committee may have and can be reached by email at ccollins@kmsonline.org or by phone at 235.2383. Thank you for considering my comments.

Insert at p.2, line 26:

All medical records reviewed and maintained by the Department pursuant to this section shall be kept confidential and shall not be disclosed except upon the order of a court of competent jurisdiction and shall not be subject to subpoena, discovery or other demand in any administrative, criminal or civil matter.



K A N S A S

RODERICK L. BREMBY, SECRETARY

KATHLEEN SEBELIUS, GOVERNOR

DEPARTMENT OF HEALTH AND ENVIRONMENT

Amendment to Newborn Hearing Screening Law, SB 511
to
House Health & Human Services Committee

by Linda Kenney
Director, Bureau for Children, Youth and Families
Kansas Department of Health and Environment

March 8, 2004

The Kansas Department of Health and Environment supports passage of SB 511.

On February 11, the Joint Committee on Administrative Rules and Regulations directed that the Newborn Hearing Screening Law K.S.A. 65-1,157a be amended to provide statutory authority for the Secretary to carry out the screening program as in the proposed newborn hearing screening rules and regulations.

Subsequently, the bill to amend the statute was introduced on the Senate side, modified as suggested by the Department, and passed.

We urge you to pass this bill and thank you for your consideration. We will be pleased to answer any questions.

*Attachment #5
HHS 3-8-04*