

MINUTES OF THE SENATE PUBLIC HEALTH AND WELFARE COMMITTEE

The meeting was called to order by Chairperson Susan Wagle at 1:45 p.m. on February 9, 2004 in Room 231-N of the Capitol.

All members were present except:

Ms. Emalene Correll, Legislative Research - excused

Committee staff present:

Ms. Terry Munchmore, Legislative Research  
Mr. Norm Furse, Revisor of Statutes  
Mrs. Diana Lee, Revisor of Statutes  
Ms. Margaret Cianciarulo, Committee Secretary

Conferees appearing before the committee:

Mr. Norm Hess, State Director of Program Services and Public Affairs for the Greater Kansas Chapter March of Dimes  
Ms. Linda Kenney, Director, Bureau for Children, Youth & Families, KDHE  
Ms. Jane Rhys, Executive Director, Kansas Council on Developmental Disabilities

Others attending:

Please See Attached List.

**Hearing on SB418 - an act establishing a birth defects information system; providing for administration by the Secretary of Health and Environment for collection of data**

Upon calling the meeting to order, Chairperson Wagle announced the first thing on the agenda was a hearing on SB418, an act establishing a birth defects information system and called upon Mr. Furse to offer an overview of the bill and the two differences between this bill and SB129, an act establishing statewide birth defects' information systems. Mr. Furse began by saying that the original version, SB129, provided a lengthy exception section to the confidentiality of medical records with the approval of the parents or guardian of the child, but is all eliminated in SB418, but in section 3, does provide for disclosure for statistical purposes. In addition, SB129 would have created a council for the Secretary to advise on the establishment of the system. This also was eliminated from SB418. Otherwise, he stated that both bills provide for the establishment of an information system to be administered by the Secretary of Health and Environment.

The Chair asked if there were questions of Mr. Furse. Senator Salmans asked if there was an objection on the first bill that the Committee heard or what prompted the change in the first bill and did it pass?

She then called upon the first proponent to testify, Mr. Norm Hess, State Director of Programs Services and Public Affairs for the Greater Kansas Chapter of March of Dimes, who stated that 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 and of that, 20% died, more than 50 babies, because of birth defects. He also stated that, according to the CDC, Kansas is one of only seven states that do not have an active reporting birth defects' information system. And lastly, he noted that the bill contains appropriate measures to protect the confidentiality of children and families. A copy of his testimony is (Attachment 1) attached hereto and incorporated into the Minutes as referenced.

The second proponent to testify was Ms. Linda Kenney, Director, Bureau for Children, Youth and Families, KDHE who also offered some statistics (ex. 30% of all admissions to pediatric hospitals are because of an illness related to a birth defect) and stated reasons why birth defects' surveillance is a critical component in the effort to reduce the impact of this health problem. (Ex. It helps to monitor occurrences of birth defects for changes in an incidence or for the presence of unusual patterns that may suggest the introduction of new teratogens, which are agents linked with fetal deformities.) A copy of her testimony is (Attachment 2) attached hereto and incorporated into the Minutes as referenced.

## CONTINUATION SHEET

MINUTES OF THE SENATE PUBLIC HEALTH AND WELFARE COMMITTEE at 1:45 p.m. on February 9, 2004 in Room 231-N of the Capitol.

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The last proponent to testify was Ms. Jane Rhys, Executive Director, Kansas Council on Developmental Disabilities, who offered a history of the council (ex. Federally mandated, no state funds, Governor appointed members including representatives of major agencies who provide services for individuals with developmental disabilities.) She also stated that this registry would provide useful information to these state agencies to assist in determining if there are any environmental problems in the state through an analysis of the types of abnormal births. A copy of her testimony is (Attachment 3) attached hereto and incorporated into the Minutes as referenced.

As there were no opponents, neutral conferees, or written testimonies, the Chair thanked those who testified, then asked the Committee for questions or comments. Questions came from Senators Salmans and Jordan regarding the availability of antidotal evidence that would point to the statement made that there are certain sectors of the state that are already having more problems, do you expect to narrow the broad term "abnormal conditions," reporting requirements, and concerns with costs (ex. such, as are you required to pay for the cost of copies?)

### **Action on the bill**

The Chair then asked the Committee if they felt prepared to work **SB418**. Senator Barnett made the motion to advance the legislation favorably. It was seconded by Senator Journey and the motion carried.

### **Approval of Minutes**

The minutes of January 27, 28, and 29, 2004, distributed at the Tuesday, February 3, 2004 stand approved as of February 6, 2004.

### **Adjournment**

As there was no further business, the meeting was adjourned. The time was 2:15 p.m.

The next meeting is scheduled for Tuesday, February 10, 2004.

# SENATE PUBLIC HEALTH AND WELFARE COMMITTEE

## GUEST LIST

DATE: Monday, February 9, 2004

NAME	REPRESENTING
Steve Kearney	MARCH OF DIMES
Mark Schreiber	self
Heather Inace	Dumron + Associates
Carolyn Maddendog	Ks St No Care
Lidia Peterell	Midland Hospice + Day Programs
Michelle Peterson	Ks. Governmental Consulting
Tom Bell	Ks. Hosp. Assn.
GARY Robbins	Ks Opt Assn
Jane Rhyo	Ks Council on Developmental Disabilities
Doug Bowman	Coordinating Council on Early Childhood
Liam Byrnes	Ass. Sen. SALMANS
Angela Harness	intern. Sen Brungardt
Mary Hillebrandt	Conlee Consulting
Christina Collins	KMS
Linda Kasey	KDHE
Norm Hess	M
Carolyn Nelson	KDHE

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*March of Dimes  
Birth Defects Foundation*

*Greater Kansas Chapter  
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**Establishing a Birth Defects Information System in Kansas  
Testimony on behalf of the March of Dimes  
Before the Senate Committee on Public Health and Welfare  
February 9, 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 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 KDHE under the current reporting system.

According to the CDC, Kansas is one of only 7 states that do not have an active reporting birth defects information system. Since 1996, 35 states have been awarded funding 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

*Senate Public Health & Welfare Committee  
Attachment 1  
Date: February 9, 2004*



# KANSAS

RODERICK L. BREMBY, SECRETARY

KATHLEEN SEBELIUS, GOVERNOR

DEPARTMENT OF HEALTH AND ENVIRONMENT

Testimony on Birth Defects Information System, SB 418

to

Senate Public Health and Welfare Committee

by Linda Kenney

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

February 9, 2004

Chairperson Wagle and members of the Committee, thank you for the opportunity to present the Department's position on SB 418. The Department strongly supports this bill. 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 preconceptual 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.

*Senate Public Health and Welfare Committee  
Attachment 2  
Feb. February 9, 2004*

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# Kansas Council on Developmental Disabilities

KATHLEEN SEBELIUS, Governor  
DAVE HEDERSTEDT, Chairperson  
JANE RHYS, Ph. D., Executive Director

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*"To ensure the opportunity to make choices regarding participation in society and quality of life for individuals with developmental disabilities"*

## PUBLIC HEALTH AND WELFARE COMMITTEE

February 9, 2004  
Room 231-N

Madame Chairperson, Members of the Committee, my name is Jane Rhys and I represent the Kansas Council on Developmental Disabilities. I am in support of Senate Bill 418, an act that establishes a birth defects registry to be administered by the Secretary of Health and Environment.

The Kansas Council is federally mandated and federally funded under the Developmental Disabilities Assistance and Bill of Rights Act of 2000. We receive no state funds. It is composed of individuals who are appointed by the Governor, including representatives of the major agencies who provide services for individuals with developmental disabilities. At least 60% of the membership is composed of individuals who are persons with developmental disabilities or their immediate relatives. Our mission is to advocate for individuals with developmental disabilities to receive adequate supports to make choices about where they live, work, and learn.

We believe that this registry would provide useful information to various state agencies that provide services to children with disabilities including the Departments of Health and Environment, Education, and Social and Rehabilitation Services. Such information could assist in determining if there are any environmental problems in the state, through an analysis of the types of abnormal births. Identification of risk factors is another benefit as is intervention and prevention of stillbirths, birth defects, and other conditions. Finally, planning for the future is an area in which each agency could benefit, knowing how many children could potentially access services allows us to be better prepared.

Senate Public Health & Welfare Committee  
Attachment 3-1  
Date: February 9, 2004

If any parent objects to the inclusion of their child in this registry, they have the option to request that their child's information be removed. We applaud the Committee for this proposal and sincerely hope that it passes.

As always, I greatly appreciate the opportunity to speak before you and would be happy to answer any questions.

Jane Rhys, Executive Director  
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