

SESSION OF 2004

**SUPPLEMENTAL NOTE ON SENATE BILL NO. 418**

As Amended by House Committee on  
Health and Human Services

**Brief\***

SB 418, as amended, concerns the establishment of a birth defects information system to be administered by the Secretary of Health and Environment. If funds are available, the bill requires the Secretary of Health and Environment to implement a statewide or pilot information system to collect information concerning congenital anomalies, stillbirths, and abnormal conditions of newborns.

If the system is implemented, the Secretary may require physicians, hospitals, and freestanding birthing centers to report information concerning patients under five years of age with a primary diagnosis of a congenital anomaly or abnormal condition, but shall not require them to report if they are already reporting the information under another provision of law. Those (physicians, hospitals, and freestanding birthing centers) providing information shall not be subject to criminal or civil liability for providing the information.

The Secretary or authorized employees of the Department can request access to the medical records of any patient defined in the bill and shall pay any associated copying costs for requests. The Secretary may review vital statistics records and shall consider expanding the list of congenital anomalies and abnormal conditions of newborns reported on birth certificates.

SB 418 also sets out the uses of the information system and stipulates that the records received and information developed for the information system are considered confidential. Any disclosed information may not identify particular individuals or sources of information. However, the Secretary may notify parents, guardians, and custodians of the children about the availability of medical care and other services. Provision is made for the removal of information for a

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\*Supplemental notes are prepared by the Legislative Research Department and do not express legislative intent. The supplemental note and fiscal note for this bill may be accessed on the Internet at <http://www.kslegislature.org>

child by the completion of a form prepared by the Secretary and provided by a local health department or physician.

Not later than 180 days after the effective date of the legislation, and subject to available funding, the Secretary shall adopt rules and regulations to:

- Implement the birth defects information system;
- Specify the types of congenital anomalies and abnormal conditions to be reported;
- Establish reporting requirements; and,
- Establish a form to use when removing children from the system and a method to distribute the form, including its availability on the internet.

Three years after its implementation, the Secretary shall prepare a report regarding the birth defects information system. The report shall be filed with the Governor, the President and Minority Leader of the Senate, the Speaker and Minority Leader of the House of Representatives, and the Departments of Social and Rehabilitation Services, Education, and Human Resources.

The House Committee amendment requires all medical records reviewed and maintained by the Department to be confidential and not to be disclosed except by court order. The records are not subject to subpoena, discovery, or other demand in any administrative, criminal, or civil matter.

## **Background**

SB 418 was introduced and supported by Senator James Barnett. Other conferees speaking in support of SB 418 included the Kansas Department of Health and Environment, the March of Dimes Greater Kansas Chapter, and the Kansas Council on Developmental Disabilities. As stated by a representative of the March of Dimes, Kansas is one of only seven states that does not have an active reporting birth defects information system. He also stated that passage of this bill would enhance the state's position in applying for funding from the Centers for Disease Control and Prevention to establish a birth defects information system. No one spoke in opposition to the bill.

SB 418 was patterned after the provisions of SB 129 introduced in the 2003 Session.

No fiscal note was available for this bill. The conferee testifying on behalf of the Department of Health and Environment stated that the Department will attempt to identify alternatives to State General Fund funding for the system and will report back to the Public Health and Welfare Committee regarding any funds received.