

SENATE BILL No. 418

AN ACT establishing a birth defects information system; providing for administration by the secretary of health and environment and for collection of data.

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

Section 1. (a) As used in sections 1 through 6, and amendments thereto:

(1) "Department" means the department of health and environment.

(2) "Freestanding birthing center" means any facility in which child birth deliveries routinely occur.

(3) "Hospital" means a hospital classified under K.S.A. 65-425, and amendments thereto, as a general hospital.

(4) "Local health department" means any county, city-county or multi-county health department created under the laws of this state.

(5) "Physician" means a person licensed to practice medicine and surgery.

(6) "Secretary" means the secretary of health and environment.

(b) The secretary of health and environment shall establish and, if funds for this purpose are available, implement a statewide or pilot birth defects information system for the collection of information concerning congenital anomalies, stillbirths and abnormal conditions of newborns.

(c) If the system is implemented under subsection (b) of this section, all of the following apply:

(1) The secretary may require each physician, hospital and freestanding birthing center to report to the system information concerning all patients under five years of age with a primary diagnosis of a congenital anomaly or abnormal condition. The secretary shall not require a hospital, freestanding birthing center or physician to report to the system any information that is reported to the secretary or department of health and environment under another provision of law.

(2) On request, each physician, hospital and freestanding birthing center shall give the secretary or authorized employees of the department of health and environment access to the medical records of any patient described in subsection (c)(1) of this section. The department shall pay the costs of copying any medical records pursuant to this act.

(3) 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.

(d) A physician, hospital or freestanding birthing center that provides information to the system under subsection (c) shall not be subject to criminal or civil liability for providing the information.

Sec. 2. The birth defects information system may be used for all of the following purposes:

(1) To identify and describe congenital anomalies, stillbirths and abnormal conditions of newborns;

(2) to detect trends and epidemics in congenital anomalies, stillbirths and abnormal conditions of newborns;

(3) to quantify morbidity and mortality of congenital anomalies and abnormal conditions of newborns;

(4) to stimulate epidemiological research regarding congenital anomalies, stillbirths and abnormal conditions of newborns;

(5) to identify risk factors for congenital anomalies, stillbirths and abnormal conditions of newborns;

(6) to facilitate intervention in and prevention of congenital anomalies, stillbirths and abnormal conditions of newborns;

(7) to facilitate access to treatment for congenital anomalies and abnormal conditions of newborns;

(8) to inform and educate the public about congenital anomalies, stillbirths and abnormal conditions of newborns.

Sec. 3. (a) Except as provided in this section, records received and information assembled by the birth defects information system pursuant to section 1, and amendments thereto, are confidential medical records. 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.

(b) The secretary may use information assembled by the system to notify parents, guardians and custodians of children with congenital

anomalies or abnormal conditions of medical care and other services available for the child and family.

(c) The secretary may disclose information assembled by the system in summary, statistical or other form that does not identify particular individuals or individual sources of information.

Sec. 4. A child's parent or legal guardian who wants information concerning the child removed from the birth defects information system shall request from the local health department or the child's physician a form prepared by the secretary. On request, a local health department or physician shall provide the form to the child's parent or legal guardian. The individual providing the form shall discuss with the child's parent or legal guardian the information contained in the system. If the child's parent or legal guardian signs the form, the local health department or physician shall forward it to the secretary. On receipt of the signed form, the secretary shall remove from the system any information that identifies the child.

Sec. 5. Not later than 180 days after the effective date of this section, the secretary of health and environment shall adopt rules and regulations in accordance with the provisions of this act to do all of the following subject to available funding:

- (a) Implement the birth defects information system;
- (b) specify the types of congenital anomalies and abnormal conditions of newborns to be reported to the system under section 1, and amendments thereto;
- (c) establish reporting requirements for information concerning diagnosed congenital anomalies and abnormal conditions of newborns;
- (d) establish a form for use by parents or legal guardians who seek to have information regarding their children removed from the system and a method of distributing the form to local health departments and to physicians. The method of distribution must include making the form available on the internet.

Sec. 6. Three years after the date a birth defects information system is implemented pursuant to section 1, and amendments thereto, and annually thereafter, the secretary shall prepare a report regarding the birth defects information system. The department shall file the report with the governor, the president and minority leader of the senate, the speaker minority leader of the house of representatives, the departments of social and rehabilitation services, education and human resources.

Sec. 7. This act shall take effect and be in force from and after its publication in the statute book.

I hereby certify that the above BILL originated in the SENATE, and passed that body

SENATE concurred in
HOUSE amendments _____

President of the Senate.

Secretary of the Senate.

Passed the HOUSE
as amended _____

Speaker of the House.

Chief Clerk of the House.

APPROVED _____

Governor.