

SENATE BILL No. 129

By Committee on Public Health and Welfare

2-3

AN ACT establishing a statewide birth defects information system; providing for administration by the secretary of health and environment and for collection of data; authorizing the use of such data for certain purposes; providing for the appointment of a council to assist in the implementation and establishment of the system.

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

Section 1. (a) As used in this section:

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

(2) "Freestanding birthing center" means any facility which is not licensed by the state and 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 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

1 the costs of copying any medical records pursuant to this act.

2 (3) The secretary may review vital statistics records and shall consider
3 expending the list of congenital anomalies and abnormal conditions of
4 newborns reported on birth certificates.

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

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

10 (1) To identify and describe congenital anomalies, stillbirths and ab-
11 normal conditions of newborns;

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

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

16 (4) to stimulate epidemiological research regarding congenital anom-
17 alies, stillbirths and abnormal conditions of newborns;

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

20 (6) to facilitate intervention in and prevention of congenital anoma-
21 lies, stillbirths and abnormal conditions of newborns;

22 (7) to facilitate access to treatment for congenital anomalies and ab-
23 normal conditions of newborns;

24 (8) to inform and educate the public about congenital anomalies, still-
25 births and abnormal conditions of newborns.

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

29 (b) (1) The secretary may use information assembled by the system
30 to notify parents, guardians and custodians of children with congenital
31 anomalies or abnormal conditions of medical care and other services avail-
32 able for the child and family.

33 (2) The secretary may disclose information assembled by the system
34 with the written consent of the parent or legal guardian of the child who
35 is the subject of the information.

36 (c) (1) Access to information assembled by the system shall be lim-
37 ited to the following persons and government entities:

38 (A) The secretary;

39 (B) authorized employees of the department of health and
40 environment;

41 (C) qualified persons or government entities that are engaged in
42 demographic, epidemiological or similar studies related to health and
43 health care provision.

1 (2) The secretary shall give a person or government entity described
2 in paragraph (1)(C) of this subsection access to the system only if the
3 person or a representative of the person or government entity signs an
4 agreement to maintain the system's confidentiality.

5 (3) The secretary shall maintain a record of all persons and govern-
6 ment entities given access to the information in the system. The record
7 shall include all of the following information:

8 (A) The name of the person who authorized access to the system;

9 (B) the name, title and organizational affiliation of the person or gov-
10 ernment entity given access to the system;

11 (C) the dates the person or government entity was given access to
12 the system;

13 (D) the specific purpose for which the person or government entity
14 intends to use the information.

15 (4) The record maintained pursuant to paragraph (3) of this subsec-
16 tion is a record open to the public.

17 (5) A person who violates an agreement described in paragraph (2)
18 of this subsection may be denied further access to confidential informa-
19 tion maintained by the secretary.

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

23 Sec. 4. A child's parent or legal guardian who wants information con-
24 cerning the child removed from the birth defects information system shall
25 request from the local health department or the child's physician a form
26 prepared by the secretary. On request, a local health department or phy-
27 sician shall provide the form to the child's parent or legal guardian. The
28 individual providing the form shall discuss with the child's parent or legal
29 guardian the information contained in the system. If the child's parent or
30 legal guardian signs the form, the local health department or physician
31 shall forward it to the secretary. On receipt of the signed form, the sec-
32 retary shall remove from the system any information that identifies the
33 child.

34 Sec. 5. (a) Within 30 days after the effective date of this act, the
35 secretary shall appoint a council to advise on the establishment and im-
36 plementation of the birth defects information system.

37 (b) The council shall include, at a minimum, members representing
38 each of the following:

39 (1) Obstetrics and gynecology;

40 (2) pediatrics;

41 (3) genetics;

42 (4) epidemiology;

43 (5) biostatistics;

- 1 (6) hospital administration;
- 2 (7) the department of social and rehabilitation services;
- 3 (8) the department of education;
- 4 (9) the department of human resources;
- 5 (10) parents of children with congenital anomalies or abnormal
- 6 conditions;
- 7 (11) the march of dimes Kansas chapter;
- 8 (12) the public.

9 (c) (1) Not later than 30 days after the initial appointments are made
10 under this section, the secretary shall convene the first meeting of the
11 council. In consultation with and with the approval of the council, the
12 secretary shall appoint, at the first meeting of the council, the chairperson
13 and vice-chairperson of the council from among the members of the
14 council. The chairperson may call additional meetings as the chairperson
15 considers appropriate.

16 (2) The council may establish rules or procedure as necessary to fa-
17 cilitate the council's orderly conduct of business.

18 (3) Council members shall serve without compensation but, to the
19 extent funds are available, shall be reimbursed for their actual and nec-
20 essary expenses incurred in the performance of their duties.

21 (d) The council shall recommend to the secretary a list of congenital
22 anomalies and abnormal conditions of newborns to be reported to the
23 system.

24 Sec. 6. Not later than 180 days after the effective date of this section,
25 the secretary of health and environment, in consultation with the council,
26 shall adopt rules and regulations in accordance with the provisions of this
27 act to do all of the following:

- 28 (A) Implement the birth defects information system;
- 29 (B) specify the types of congenital anomalies and abnormal condi-
30 tions of newborns to be reported to the system under section 1, and
31 amendments thereto;
- 32 (C) establish reporting requirements for information concerning di-
33 agnosed congenital anomalies and abnormal conditions of newborns;
- 34 (D) establish standards that must be met by persons or government
35 entities that seek access to the system;
- 36 (E) establish a form for use by parents or legal guardians who seek
37 to have information regarding their children removed from the system
38 and a method of distributing the form to local health departments and to
39 physicians. The method of distribution must include making the form
40 available on the internet.

41 Sec. 7. Three years after the date a birth defects information system
42 is implemented pursuant to section 1, and amendments thereto, and an-
43 nually thereafter, the secretary shall prepare a report regarding the birth

1 defects information system. The council created under section 5, and
2 amendments thereto, shall, not later than two years after the date a birth
3 defects information system is implemented, specify the information the
4 department is to include in each report. The department shall file the
5 report with the governor, the president and minority leader of the senate,
6 the speaker and minority leader of the house of representative, the de-
7 partments of social and rehabilitation services, education and human
8 resources.

9 Sec. 8. This act shall take effect and be in force from and after its
10 publication in the statute book.

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