

CHAPTER 287**(SB 219)**

AN ACT relating to the Kentucky Birth Surveillance Registry.

Be it enacted by the General Assembly of the Commonwealth of Kentucky:

Section 1. KRS 211.660 is amended to read as follows:

- (1) The Department for Public Health shall establish and maintain a Kentucky birth surveillance registry that will provide a system for the collection of information concerning birth defects, stillbirths, and high-risk conditions. The system may cover all or part of the Commonwealth.
- (2) In establishing the system, the department may review vital statistics records, and shall also consider expanding the current list of congenital anomalies and high-risk conditions as reported on birth certificates.
- (3) (a) The department may require general acute-care hospitals licensed under ~~the provisions of~~ KRS Chapter 216B to maintain a list of ~~the following information:~~ all inpatients **and voluntarily to maintain a list of all outpatients** up to the age of five (5) years with a primary diagnosis of a congenital anomaly or high-risk condition as defined by the department upon the recommendation of the appointed advisory committee. ***Hospital participation regarding its outpatients shall be voluntary and subject to the discretion of each hospital.***

(b) ***The department may require medical laboratories licensed under KRS Chapter 333 to maintain medical records for all persons up to the age of five (5) years with a primary diagnosis of or a laboratory test result indicating congenital anomaly or high-risk condition as defined by the department upon the recommendation of the appointed advisory committee.***
- (4) Each licensed free-standing birthing center, ~~and~~ general acute-care hospital licensed under KRS Chapter 216B, **and medical laboratory licensed under KRS Chapter 333** shall grant, ***if required or otherwise participating voluntarily under the provisions of subsection (3) of this section,*** to any Kentucky Birth Surveillance Registry personnel or his or her designee, upon presentation of proper identification, access to the medical records of any patient meeting the criteria in subsection (3) of this section. If the department's agent determines that copying of the medical records is necessary, associated costs shall be borne by the Department for Public Health at the rate pursuant to KRS 422.317.
- (5) No liability of any kind, character, damages, or other relief shall arise or be enforced against any licensed free-standing birthing center, ~~or~~ general acute-care hospital, **or medical laboratory** by reason of having provided the information or material to the Kentucky Birth Surveillance Registry.
- (6) The Department for Public Health may implement the provisions of KRS 211.651 to 211.670 through the promulgation of administrative regulations in accordance with the provisions of KRS Chapter 13A.

Section 2. KRS 211.665 is amended to read as follows:

- (1) The secretary shall appoint a committee to advise on the implementation of the Kentucky birth surveillance registry. The advisory committee shall have representation from the disciplines of obstetrics and gynecology, pediatrics, genetics, epidemiology, biostatistics, hospital administration, state agency service providers, parents of children with congenital

anomalies, or high risk conditions, and consumers. Other disciplines may be represented at the discretion of the secretary.

- (2) The advisory committee shall recommend to the department a definition of congenital anomalies and high risk conditions to be reported to the registry.
- (3) If the department determines it is necessary to collect information from sources other than vital statistics records, general acute care hospitals, *medical laboratories*, and free-standing birthing centers, the department shall consult with the advisory committee prior to requesting the information.

Section 3. KRS 211.670 is amended to read as follows:

- (1) All lists *and medical records* maintained by hospitals *and medical laboratories* pursuant to KRS 211.660 shall be confidential. All information collected and analyzed pursuant to KRS 211.660 and 211.665 shall be held confidential as to the identity of the individual patient. Staff of the cabinet, the department, or its designee may use the information to notify parents of available medical care and other services available for the child and family. Further disclosure shall be made only pursuant to the written consent of the child's parent or legal guardian.
- (2) Access to information assembled by the Kentucky birth surveillance registry shall be limited to the cabinet, the department, or its designee and to qualified persons or organizations engaged in demographic, epidemiological or other similar studies related to health and health care provision. A written agreement to maintain confidentiality shall be required if access is approved for persons other than representatives of the cabinet.
- (3) The department shall maintain a record of all persons given access to the information in the Kentucky birth surveillance registry. The record shall include: the name of the person authorizing access; name, title, and organizational affiliation of person given access; dates of access; and the specific purpose for which information is to be used. This record of access shall be open to public inspection during normal operating hours of the department.
- (4) Information assembled by the Kentucky birth surveillance registry may be disclosed in summary, statistical, or other form which does not identify particular individuals or individual sources of information.
- (5) Any person who, in violation of a written agreement to maintain confidentiality, discloses any information provided under KRS 211.660 and 211.665 may be denied further access to confidential information maintained by the department.

Approved April 9, 2002