WEST VIRGINIA LEGISLATURE
Regular Session, 2002

ENROLLED
Committee Substitute for
SENATE BILL NO. 672

(By Senator Helmick et al)

PASSED March 9, 2002

In Effect ninety days from Passage
AN ACT to amend chapter sixteen of the code of West Virginia, one thousand nine hundred thirty-one, as amended, by adding thereto a new article, designated article forty, relating to the establishment and implementation of a statewide birth defects information system by the commissioner of the bureau for public health.

Be it enacted by the Legislature of West Virginia:

That chapter sixteen of the code of West Virginia, one thousand nine hundred thirty-one, as amended, be amended by adding thereto a new article, designated article forty, to read as follows:

ARTICLE 40. STATEWIDE BIRTH DEFECTS INFORMATION SYSTEM.
§16-40-1. Definitions.

As used in this article:

(1) "Commissioner" means the commissioner of the bureau for public health.

(2) "Freestanding birthing center" means any health care facility in which births routinely occur, regardless of whether the facility is located on the campus of another health care facility, and which is not licensed under article five-b of this chapter.

(3) "Hospital" means a hospital licensed under the provisions of article five-b of this chapter.

(4) "Nurse-midwife" means an individual authorized under article fifteen, chapter thirty of this code to practice nurse-midwifery.

(5) "Physician" means an individual authorized under article three or fourteen, chapter thirty of this code to practice medicine and surgery or osteopathic medicine and surgery.

§16-40-2. Expansion and implementation of statewide birth defects information system.

(a) The commissioner shall establish and implement a statewide birth defects information system for the collection of information concerning congenital anomalies, stillbirths and abnormal conditions of newborns.

(b) The commissioner may require each physician, nurse-midwife, hospital and freestanding birthing center to report to the system information concerning all patients under six years of age with a primary diagnosis of a congenital anomaly or abnormal condition: Provided, That the commissioner may not require the reporting of personal identifying information or enter into the system any personal identifying information regarding congenital anomalies or abnormal conditions of a child whose parent
14 or legal guardian objects on the basis of religious belief.
15 The commissioner may not require a hospital, freestanding
16 birthing center, nurse-midwife or physician to report to
17 the system any information that is required to be reported
18 to the commissioner or the bureau for public health under
19 another provision of this code.

20 (c) On request, each physician, nurse-midwife, hospital
21 and freestanding birthing center shall give the commis­
22 sioner or authorized employees of the bureau access to the
23 medical records of any patient described in subsection (b)
24 of this section. The bureau shall pay the costs of copying
25 any medical records pursuant to this section.

26 (d) A physician, nurse-midwife, hospital or freestanding
27 birthing center that provides information to the system
28 under subsection (b) of this section is not subject to
29 criminal or civil liability for providing the information.

§16-40-3. Purposes of system.

1 The birth defects information system may be used for all
2 of the following purposes:
3
4 (1) To identify and describe congenital anomalies,
5 stillbirths and abnormal conditions of newborns;
6
7 (2) To detect trends and epidemics in congenital anoma­
8 lies, stillbirths and abnormal conditions of newborns;
9
10 (3) To quantify morbidity and mortality of congenital
11 anomalies and abnormal conditions of newborns;
12
13 (4) To stimulate epidemiological research regarding
14 congenital anomalies, stillbirths and abnormal conditions
15 of newborns;
16
17 (5) To identify risk factors for congenital anomalies,
18 stillbirths and abnormal conditions of newborns;
19
20 (6) To facilitate intervention in and prevention of
21 congenital anomalies, stillbirths and abnormal conditions
22 of newborns;
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(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.


(a) Except as provided in this section, records received and information assembled by the birth defects information system pursuant to section two of this article are confidential medical records.

(b) (1) The commissioner 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.

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

(c) (1) Access to information assembled by the system is limited to the following persons and government entities:

(A) The commissioner;

(B) Authorized employees of the bureau; and

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

(2) The commissioner shall give a person or government entity described in subparagraph (C), subdivision (1) of this subsection access to the system only for informational requests of data and only if the person or a representative of the person or government entity signs an agreement to maintain the system's confidentiality.
27 (3) The commissioner shall maintain a record of all
28 persons and government entities given access to the
29 information in the system. The record shall include all of
30 the following information:
31
32 (A) The name of the person who authorized access to the
33 system;
34
35 (B) The name, title and organizational affiliation of the
36 person or government entity given access to the system;
37
38 (C) The dates the person or government entity was given
39 access to the system; and
40
41 (D) The specific purpose for which the person or govern-
42 ment entity intends to use the information.
43
44 (4) The record maintained pursuant to subdivision (3) of
45 this subsection is a public record as defined in chapter
46 twenty-nine-b of this code.
47
48 (5) A person who violates an agreement described in
49 subdivision (2) of this subsection shall be denied further
50 access to confidential information maintained by the
51 commissioner.
52
53 (d) The commissioner may disclose information assem-
54 bled by the system in summary, statistical or other form
55 that does not identify particular individuals or individual
56 sources of information.

§16-40-5. Parent or legal guardian may require removal of
information concerning child from system.

1 (a) As used in this section, "local board of health" means
2 a local board of health established under the provisions of
3 article two of this chapter.
4
5 (b) A child's parent or legal guardian who wants infor-
6 mation concerning the child removed from the birth
7 defects information system shall request from the local
8 board of health or the child's physician a form prepared by
the commissioner. On request, a local board of health 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 board of health or physician shall forward it to the commissioner. On receipt of the signed form, the commissioner shall remove from the follow-up system any information that identifies the child. All personal identifying information may be removed from the record: Provided, That the record itself shall remain in the system for reporting and analysis purposes.

§16-40-6. Advisory council.

(a) Not later than thirty days after the effective date of this article, the commissioner shall appoint a council to advise on the establishment and implementation of the birth defects information system.

(b) The council shall include, at a minimum, persons representing each of the following interests:

(1) Obstetrics and gynecology;
(2) Pediatrics;
(3) Genetics;
(4) Epidemiology;
(5) Biostatistics;
(6) Hospital administration;
(7) The department of education;
(8) Parents of children with congenital anomalies or abnormal conditions;
(9) The march of dimes West Virginia state chapter; and
(10) The public.
(c) (1) Not later than thirty days after the initial appointments are made under subsection (b) of this section, the commissioner shall convene the first meeting of the council. In consultation with and with the approval of the council, the commissioner shall appoint, at the first meeting of the council, the chairperson and vice chairperson of the council. The chairperson may call additional meetings as the chairperson considers appropriate.

(2) The council may establish rules of procedure as necessary to facilitate the council's orderly conduct of business.

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

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


Not later than the first day of July, two thousand three, the commissioner shall, in consultation with the council created under section six of this article, propose rules for legislative approval in accordance with the provisions of article three, chapter twenty-nine-a of this code to do all of the following:

(1) Implement the birth defects information system;

(2) Specify the types of congenital anomalies and abnormal conditions of newborns to be reported to the system under section two of this article;

(3) Establish reporting requirements for information concerning diagnosed congenital anomalies and abnormal conditions of newborns;
(4) Establish standards that are required to be met by persons or government entities that seek access to the system; and

(5) 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 boards of health and to physicians. The method of distribution must include making the form available on the internet.

§16-40-8. Reports by commissioner.

Prior to the first day of January, three years after the date a birth defects information system is implemented pursuant to this article, and by the first day of January of each year after that, the commissioner shall prepare a report regarding the birth defects information system. The council created under section six of this article shall, not later than two years after the date a birth defects information system is implemented, specify the information the commissioner is to include in each report. The commissioner shall file the report with the governor and the joint committee on government and finance.
The Joint Committee on Enrolled Bills hereby certifies that the foregoing bill is correctly enrolled.

Chairman Senate Committee

Originated in the Senate.

In effect ninety days from passage.

Clerk of the Senate

Clerk of the House of Delegates

President of the Senate

Speaker House of Delegates

The within is approved this the 28th Day of

Governor

2002.