

SB 672

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OFFICE WEST VIRGINIA
SECRETARY OF STATE

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**

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COMMITTEE SUBSTITUTE

FOR

Senate Bill No. 672

(SENATORS HELMICK, FANNING, BOLEY, PREZIOSO,
ROSS AND ANDERSON, *original sponsors*)

[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.

1 As used in this article:

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

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

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

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

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

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

1 (a) The commissioner shall establish and implement a
2 statewide birth defects information system for the collec-
3 tion of information concerning congenital anomalies,
4 stillbirths and abnormal conditions of newborns.

5 (b) The commissioner may require each physician,
6 nurse-midwife, hospital and freestanding birthing center
7 to report to the system information concerning all patients
8 under six years of age with a primary diagnosis of a
9 congenital anomaly or abnormal condition: *Provided*, That
10 the commissioner may not require the reporting of per-
11 sonal identifying information or enter into the system any
12 personal identifying information regarding congenital
13 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 (1) To identify and describe congenital anomalies,
4 stillbirths and abnormal conditions of newborns;

5 (2) To detect trends and epidemics in congenital anoma-
6 lies, stillbirths and abnormal conditions of newborns;

7 (3) To quantify morbidity and mortality of congenital
8 anomalies and abnormal conditions of newborns;

9 (4) To stimulate epidemiological research regarding
10 congenital anomalies, stillbirths and abnormal conditions
11 of newborns;

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

14 (6) To facilitate intervention in and prevention of
15 congenital anomalies, stillbirths and abnormal conditions
16 of newborns;

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

19 (8) To inform and educate the public about congenital
20 anomalies, stillbirths and abnormal conditions of new-
21 borns.

§16-40-4. Confidentiality of information.

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

5 (b) (1) The commissioner may use information assembled
6 by the system to notify parents, guardians and custodians
7 of children with congenital anomalies or abnormal condi-
8 tions of medical care and other services available for the
9 child and family.

10 (2) The commissioner may disclose information assem-
11 bled by the system with the written consent of the parent
12 or legal guardian of the child who is the subject of the
13 information.

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

16 (A) The commissioner;

17 (B) Authorized employees of the bureau; and

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

21 (2) The commissioner shall give a person or government
22 entity described in subparagraph (C), subdivision (1) of
23 this subsection access to the system only for informational
24 requests of data and only if the person or a representative
25 of the person or government entity signs an agreement to
26 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 (A) The name of the person who authorized access to the
32 system;

33 (B) The name, title and organizational affiliation of the
34 person or government entity given access to the system;

35 (C) The dates the person or government entity was given
36 access to the system; and

37 (D) The specific purpose for which the person or govern-
38 ment entity intends to use the information.

39 (4) The record maintained pursuant to subdivision (3) of
40 this subsection is a public record as defined in chapter
41 twenty-nine-b of this code.

42 (5) A person who violates an agreement described in
43 subdivision (2) of this subsection shall be denied further
44 access to confidential information maintained by the
45 commissioner.

46 (d) The commissioner may disclose information assem-
47 bled by the system in summary, statistical or other form
48 that does not identify particular individuals or individual
49 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 (b) A child's parent or legal guardian who wants infor-
5 mation concerning the child removed from the birth
6 defects information system shall request from the local
7 board of health or the child's physician a form prepared by

8 the commissioner. On request, a local board of health or
9 physician shall provide the form to the child's parent or
10 legal guardian. The individual providing the form shall
11 discuss with the child's parent or legal guardian the
12 information contained in the system. If the child's parent
13 or legal guardian signs the form, the local board of health
14 or physician shall forward it to the commissioner. On
15 receipt of the signed form, the commissioner shall remove
16 from the follow-up system any information that identifies
17 the child. All personal identifying information may be
18 removed from the record: *Provided*, That the record itself
19 shall remain in the system for reporting and analysis
20 purposes.

§16-40-6. Advisory council.

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

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

- 7 (1) Obstetrics and gynecology;
- 8 (2) Pediatrics;
- 9 (3) Genetics;
- 10 (4) Epidemiology;
- 11 (5) Biostatistics;
- 12 (6) Hospital administration;
- 13 (7) The department of education;
- 14 (8) Parents of children with congenital anomalies or
15 abnormal conditions;
- 16 (9) The march of dimes West Virginia state chapter; and
17 (10) The public.

18 (c) (1) Not later than thirty days after the initial appoint-
19 ments are made under subsection (b) of this section, the
20 commissioner shall convene the first meeting of the
21 council. In consultation with and with the approval of the
22 council, the commissioner shall appoint, at the first
23 meeting of the council, the chairperson and vice chairper-
24 son of the council from among the members of the council.
25 The chairperson may call additional meetings as the
26 chairperson considers appropriate.

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

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

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

§16-40-7. Rules.

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

7 (1) Implement the birth defects information system;

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

11 (3) Establish reporting requirements for information
12 concerning diagnosed congenital anomalies and abnormal
13 conditions of newborns;

14 (4) Establish standards that are required to be met by
15 persons or government entities that seek access to the
16 system; and

17 (5) Establish a form for use by parents or legal guardians
18 who seek to have information regarding their children
19 removed from the system and a method of distributing the
20 form to local boards of health and to physicians. The
21 method of distribution must include making the form
22 available on the internet.

§16-40-8. Reports by commissioner.

1 Prior to the first day of January, three years after the
2 date a birth defects information system is implemented
3 pursuant to this article, and by the first day of January of
4 each year after that, the commissioner shall prepare a
5 report regarding the birth defects information system. The
6 council created under section six of this article shall, not
7 later than two years after the date a birth defects informa-
8 tion system is implemented, specify the information the
9 commissioner is to include in each report. The commis-
10 sioner shall file the report with the governor and the joint
11 committee on government and finance.

The Joint Committee on Enrolled Bills hereby certifies that the foregoing bill is correctly enrolled.

[Signature]
.....
Chairman Senate Committee

[Signature]
.....
Chairman House Committee

Originated in the Senate.

In effect ninety days from passage.

[Signature]
.....
Clerk of the Senate

[Signature]
.....
Clerk of the House of Delegates

[Signature]
.....
President of the Senate

[Signature]
.....
Speaker House of Delegates

The within *is approved* this the *28th*
Day of *March*, 2002.

[Signature]
.....
Governor

PRESENTED TO THE
GOVERNOR

Date 3/26/02

Time 3:00 pm