
By: **Chairman, Health and Government Operations Committee (By
Request - Departmental - Health and Mental Hygiene)**

Introduced and read first time: February 11, 2005

Assigned to: Health and Government Operations

A BILL ENTITLED

1 AN ACT concerning

2 **Maryland Birth Defects Program - Authority to Obtain Medical Information**

3 FOR the purpose of clarifying the circumstances under which cases of birth defects
4 must be reported and hospital records and other medical information relative to
5 those cases is required to be provided to the Department of Health and Mental
6 Hygiene under Maryland's birth defects reporting law; allowing for the release
7 of the identity of children without birth defects and certain other information to
8 the Department in connection with certain public health investigations;
9 providing that the release of medical information under certain circumstances is
10 not a breach of patient confidentiality; providing for certain immunity under
11 certain circumstances; requiring the Department to follow certain laws
12 regarding the protection of human subjects; requiring the Department to keep
13 the medical information confidential; and generally relating to birth defects
14 reporting.

15 BY repealing and reenacting, with amendments,
16 Article - Health - General
17 Section 18-206
18 Annotated Code of Maryland
19 (2000 Replacement Volume and 2004 Supplement)

20 SECTION 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF
21 MARYLAND, That the Laws of Maryland read as follows:

22 **Article - Health - General**

23 18-206.

24 (a) (1) In this section[,] THE FOLLOWING WORDS HAVE THE MEANINGS
25 INDICATED.

26 (2) "[sentinel birth] BIRTH defect" includes:

27 [(1)] (I) Anencephaly;

- 1 [(2)] (II) Spina bifida;
- 2 [(3)] (III) Hydrocephaly;
- 3 [(4)] (IV) Cleft palate;
- 4 [(5)] (V) Cleft lip;
- 5 [(6)] (VI) Esophageal atresia and stenosis;
- 6 [(7)] (VII) Rectal and anal atresia;
- 7 [(8)] (VIII) Hypospadias;
- 8 [(9)] (IX) Reduction deformity - upper limb;
- 9 [(10)] (X) Reduction deformity - lower limb;
- 10 [(11)] (XI) Congenital dislocation of the hip; and
- 11 [(12)] (XII) Down syndrome.

12 (3) "HEALTH CARE PROVIDER" HAS THE MEANING STATED IN § 4-301 OF
13 THIS ARTICLE.

14 (b) (1) A hospital shall make a report on each child who is [born live]
15 LIVEBORN or stillborn in the hospital and has a [sentinel] birth defect. If a child is
16 born outside the hospital, the person filling out the birth certificate shall make a
17 report under this section.

18 (2) The Secretary shall appoint a committee of physicians, hospital
19 representatives and officials from the Department to determine the information
20 required under paragraph (1) of this subsection.

21 (3) Each month the hospital shall submit the reports for that month to
22 the Department.

23 (C) A HEALTH CARE PROVIDER SHALL ALLOW THE DEPARTMENT TO INSPECT
24 AND OBTAIN COPIES OF ANY OF THE FOLLOWING INFORMATION RELATING TO A
25 CHILD WITH A BIRTH DEFECT PROVIDED THAT THE INFORMATION IS USED FOR THE
26 PURPOSES DESCRIBED IN SUBSECTION (F) OF THIS SECTION:

- 27 (1) MEDICAL RECORDS;
- 28 (2) RECORDS OF LABORATORY TESTS; AND
- 29 (3) ANY OTHER MEDICAL INFORMATION.

30 [(c)] (D) (1) The hospital shall disclose the identity of the child with a birth
31 defect, OR A CHILD WITHOUT A BIRTH DEFECT WHO IS PART OF AN INVESTIGATION

1 BY THE DEPARTMENT UNDER PARAGRAPH (2) OF THIS SUBSECTION, to the Secretary
2 so that the Secretary may:

3 (i) Use the information to protect the public health; or

4 (ii) Provide the parents OF CHILDREN WITH BIRTH DEFECTS with
5 information on [sentinel] birth defects and public and private services available in
6 accordance with paragraphs (1) and (4) of subsection [(d)] (J) of this section.

7 (2) (I) If the Department shows a need for the individual identity of
8 children without [sentinel] birth defects to conduct [a case-control] AN investigation
9 IN ITS EFFORTS TO PROTECT THE PUBLIC HEALTH, the hospital shall [obtain the
10 written consent of the parent or guardian of the child to disclose the child's name to
11 the Secretary] PROVIDE THE SECRETARY WITH A LIST OF CHILDREN WITH
12 CHARACTERISTICS THAT MEET CRITERIA SPECIFIED BY THE DEPARTMENT FOR ITS
13 INVESTIGATION.

14 (II) THE DEPARTMENT SHALL OBTAIN THE INFORMED CONSENT OF
15 THE PARENT OR GUARDIAN OF A CHILD WITHOUT A BIRTH DEFECT BEFORE
16 OBTAINING THE MEDICAL RECORDS OF THE CHILD OR INCLUDING THE CHILD IN
17 ANY RESEARCH.

18 (3) The Secretary shall assure that the identity of a child under this
19 section may not be released OUTSIDE OF THE DEPARTMENT without the written
20 consent of the parent or guardian of the child.

21 (E) THE DEPARTMENT SHALL KEEP ANY MEDICAL INFORMATION OBTAINED
22 UNDER THIS SECTION CONFIDENTIAL.

23 (F) MEDICAL INFORMATION REQUESTED UNDER THIS SECTION MUST BE:

24 (1) RELEVANT TO:

25 (I) ASSURING THE QUALITY OF THE DATA REPORTED;

26 (II) PROVIDING INFORMATION OR SERVICES TO THE CHILD'S
27 FAMILY;

28 (III) CONDUCTING AN EPIDEMIOLOGICAL INVESTIGATION RELATED
29 TO A BIRTH DEFECT; OR

30 (IV) CONDUCTING THE DEPARTMENT'S RESEARCH INTO THE
31 CAUSES OF BIRTH DEFECTS; AND

32 (2) ONLY AS INTRUSIVE AS NECESSARY.

33 (G) RELEASE OF REPORTS AND OTHER MEDICAL INFORMATION TO THE
34 DEPARTMENT IN ACCORDANCE WITH THIS SECTION IS NOT A VIOLATION OF THE
35 CONFIDENTIAL RELATIONSHIP BETWEEN A HEALTH CARE PROVIDER AND A
36 PATIENT.

1 (H) A HEALTH CARE PROVIDER MAY NOT BE HELD LIABLE FOR DAMAGES AND
2 IS NOT SUBJECT TO CRIMINAL PENALTIES FOR PROVIDING PATIENT INFORMATION
3 TO THE DEPARTMENT AS AUTHORIZED BY THIS SECTION.

4 (I) WHENEVER THE DEPARTMENT ENGAGES IN HUMAN SUBJECT RESEARCH,
5 THE DEPARTMENT IS REQUIRED TO FOLLOW FEDERAL AND STATE LAWS REGARDING
6 THE PROTECTION OF HUMAN SUBJECTS.

7 [(d)] (J) (1) The Department shall assure that information is prepared and
8 periodically updated on:

9 (i) [Sentinel birth] BIRTH defects; and

10 (ii) Public and private services for [the disabled] CHILDREN with
11 [sentinel] birth defects.

12 (2) (i) The Secretary shall appoint a committee to determine the
13 information required under paragraph (1) of this subsection.

14 (ii) The committee shall consist of:

15 1. Physicians;

16 2. Educators;

17 3. Social service specialists;

18 4. Representatives of the Department;

19 5. Representatives of the Department of Human Resources;

20 6. Representatives of the Department of Education; and

21 7. Parents of children with [sentinel] birth defects.

22 (3) The information provided under this subsection shall be distributed
23 to each hospital and made available to parents or guardians of children with
24 [sentinel] birth defects by the [infant's] CHILD'S physician before the [infant]
25 CHILD is discharged from the hospital and with an explanation, to the extent possible,
26 of the birth defect to the parents or guardians.

27 (4) (i) The Secretary shall send a letter to the parent or guardian of
28 each child reported under this section with a [sentinel] birth defect before the child is
29 6 months old.

30 (ii) The letter shall offer information about the birth defect and
31 available services with emphasis on needs identified after discharge from the
32 hospital.

1 (iii) Before sending a letter to a parent or guardian, the Secretary
2 shall implement appropriate procedures to assure that a letter is not sent to a parent
3 or guardian of a child who has died.

4 [(e)] (K) The Department and the Department of the Environment shall
5 jointly develop procedures to monitor the data on [sentinel] birth defect trends which
6 may be caused by environmental hazards.

7 SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take
8 effect October 1, 2005.