

By: Laubenberg, Crownover

H.B. No. 411

A BILL TO BE ENTITLED

AN ACT

relating to the confidentiality of newborn screening information.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF TEXAS:

SECTION 1. Section 33.017, Health and Safety Code, as added by Chapter 179 (H.B. 1672), Acts of the 81st Legislature, Regular Session, 2009, is amended by amending Subsections (a), (b), and (c) and adding Subsections (a-1), (c-1), (e), (f), (g), and (h) to read as follows:

(a) In this section:

(1) "Affiliated with a health agency" means a person who is an employee or former employee of a health agency.

(2) "Commission" means the Health and Human Services Commission.

(3) "Commissioner" means the commissioner of state health services.

(4) "Health agency" means the commission and the health and human services agencies listed in Section 531.001, Government Code.

(5) "Public health purpose" means a purpose that relates to cancer, a birth defect, an infectious disease, a chronic disease, environmental exposure, or newborn screening.

(a-1) Reports, records, and information obtained or developed by the department under this chapter are confidential and are not subject to disclosure under Chapter 552, Government Code,

1 are not subject to subpoena, and may not otherwise be released or
2 made public except as provided by this section.

3 (b) Notwithstanding other law, reports, records, and
4 information obtained or developed by the department under this
5 chapter may be disclosed:

6 (1) for purposes of diagnosis or follow-up authorized
7 under Section 33.014;

8 (2) with the consent of each identified individual or
9 an individual authorized to consent on behalf of an identified
10 child;

11 (3) as authorized by court order;

12 (4) to a medical examiner authorized to conduct an
13 autopsy on a child or an inquest on the death of a child; or

14 (5) to public health programs of the department for
15 public health research purposes, provided that the disclosure is
16 approved by:

17 (A) the commissioner or the commissioner's
18 designee; and

19 (B) an institutional review board or privacy
20 board of the department as authorized by the federal privacy
21 requirements adopted under the Health Insurance Portability and
22 Accountability Act of 1996 (Pub. L. No. 104-191) contained in 45
23 C.F.R. Part 160 and 45 C.F.R. Part 164, Subparts A and E.

24 (c) Notwithstanding other law, reports, records, and
25 information that do not identify a child or the family of a child
26 may be released without consent if the disclosure is for:

27 (1) statistical purposes;

1 (2) purposes related to obtaining or maintaining
2 federal certification, including related [~~approval, or~~] quality
3 assurance, for:

4 (A) the department's laboratory; or

5 (B) a public or private laboratory to perform
6 newborn screening tests that are not part of inter-laboratory
7 exchanges required for federal certification of the department's
8 laboratory, provided that the disclosure is approved by the
9 commissioner or the commissioner's designee;

10 (3) purposes relating to:

11 (A) review or [~~or~~] quality assurance [~~or~~
12 ~~improvement~~] of the department's newborn screening under this
13 chapter or the department's newborn screening program services
14 under Subchapter C; or

15 (B) improvement of the department's newborn
16 screening under this chapter or the department's newborn screening
17 program services under Subchapter C, provided that the disclosure
18 is approved by the commissioner or the commissioner's designee; or

19 (4) other [~~research purposes, provided that the~~
20 ~~disclosure is approved by an institutional review board or privacy~~
21 ~~board of the department; or~~

22 [~~5~~] quality assurance purposes related to public
23 health testing equipment and supplies, provided that the disclosure
24 is approved by:

25 (A) the commissioner or the commissioner's
26 designee [~~assessment is performed by a person who is not a~~
27 ~~laboratory]; and~~

1 (B) ~~[only newborn screening specimens are~~
2 ~~disclosed; and~~

3 ~~[(C) the disclosure is approved by]~~ an
4 institutional review board or privacy board of the department.

5 (c-1) Notwithstanding other law, reports, records, and
6 information that do not identify a child or the family of a child
7 may be released for public health research purposes if:

8 (1) a parent of the child consents to the disclosure;
9 and

10 (2) the disclosure is approved by:

11 (A) an institutional review board or privacy
12 board of the department; and

13 (B) the commissioner or the commissioner's
14 designee.

15 (e) If disclosure is approved by the commissioner or the
16 commissioner's designee under Subsection (c)(4) or (c-1), the
17 department shall post notice on the newborn screening web page on
18 the department's Internet website that disclosure has been
19 approved. The commissioner shall determine the form and content of
20 the notice.

21 (f) In accordance with this section, the commissioner or the
22 commissioner's designee:

23 (1) may approve disclosure of reports, records, or
24 information obtained or developed under this chapter only for a
25 public health purpose; and

26 (2) may not approve disclosure of reports, records, or
27 information obtained or developed under this chapter for purposes

1 related to forensic science or health insurance underwriting.

2 (g) An institutional review board or privacy board of the
3 department that approves disclosure under this section must include
4 at least three persons who are not affiliated with a health agency,
5 one of whom must be a member of the public.

6 (h) The requirement that consent be obtained before certain
7 disclosures of reports, records, or information may be made under
8 this section does not affect the requirement that screening tests
9 be performed under Section 33.011.

10 SECTION 2. This Act takes effect immediately if it receives
11 a vote of two-thirds of all the members elected to each house, as
12 provided by Section 39, Article III, Texas Constitution. If this
13 Act does not receive the vote necessary for immediate effect, this
14 Act takes effect September 1, 2011.