

By: Laubenberg

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 (b) and (c) and adding Subsections (e), (f), and (g) to read as follows:

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

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

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

(3) as authorized by court order;

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

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

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

(B) an institutional review board or privacy

1 board of the department as authorized by the federal privacy  
2 requirements adopted under the Health Insurance Portability and  
3 Accountability Act of 1996 (Pub. L. No. 104-191) contained in 45  
4 C.F.R. Part 160 and 45 C.F.R. Part 164, Subparts A and E.

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

8 (1) statistical purposes;

9 (2) purposes related to obtaining or maintaining  
10 federal certification, including related [~~approval, or~~]  
11 assurance, for:

12 (A) the department's laboratory; or

13 (B) a public or private laboratory to perform  
14 newborn screening tests that are not part of inter-laboratory  
15 exchanges required for federal certification of the department's  
16 laboratory, provided that the disclosure is approved by the  
17 commissioner or the commissioner's designee;

18 (3) purposes relating to:

19 (A) review or [~~or~~]  
20 ~~improvement~~ quality assurance [~~or~~]  
21 of the department's newborn screening under this  
22 chapter or the department's newborn screening program services  
23 under Subchapter C; or

24 (B) improvement of the department's newborn  
25 screening under this chapter or the department's newborn screening  
26 program services under Subchapter C, provided that the disclosure  
27 is approved by the commissioner or the commissioner's designee;

(4) public health research purposes, provided that the

1 disclosure is approved by:

2 (A) an institutional review board or privacy  
3 board of the department; and

4 (B) the commissioner; or

5 (5) other quality assurance purposes related to public  
6 health testing equipment and supplies, provided that the disclosure  
7 is approved by:

8 (A) the commissioner [~~assessment is performed by~~  
9 ~~a person who is not a laboratory~~]; and

10 (B) [~~only newborn screening specimens are~~  
11 ~~disclosed; and~~

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

14 (e) If disclosure is approved by the commissioner under  
15 Subsection (c)(4) or (5), the department shall post notice on the  
16 newborn screening web page on the department's Internet website  
17 that disclosure has been approved. The commissioner shall  
18 determine the form and content of the notice.

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

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

24 (2) may not approve disclosure of reports, records, or  
25 information obtained or developed under this chapter for purposes  
26 related to forensic science or health insurance underwriting.

27 (g) In this section, "commissioner" means the commissioner

1 of state health services.

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