

1-1 By: Laubenberg, Crownover (Senate Sponsor - Deuell) H.B. No. 411
1-2 (In the Senate - Received from the House April 12, 2011;
1-3 April 20, 2011, read first time and referred to Committee on Health
1-4 and Human Services; May 19, 2011, reported adversely, with
1-5 favorable Committee Substitute by the following vote: Yeas 5,
1-6 Nays 1; May 19, 2011, sent to printer.)

1-7 COMMITTEE SUBSTITUTE FOR H.B. No. 411 By: Deuell

1-8 A BILL TO BE ENTITLED
1-9 AN ACT

1-10 relating to the confidentiality of newborn screening information.
1-11 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF TEXAS:
1-12 SECTION 1. Section 33.017, Health and Safety Code, as added
1-13 by Chapter 179 (H.B. 1672), Acts of the 81st Legislature, Regular
1-14 Session, 2009, is amended by amending Subsections (a), (b), and (c)
1-15 and adding Subsections (a-1), (c-1), (e), (f), (g), (h), and (i) to
1-16 read as follows:
1-17 (a) In this section:
1-18 (1) "Affiliated with a health agency" means a person
1-19 who is an employee or former employee of a health agency.
1-20 (2) "Commission" means the Health and Human Services
1-21 Commission.
1-22 (3) "Commissioner" means the commissioner of state
1-23 health services.
1-24 (4) "Health agency" means the commission and the
1-25 health and human services agencies listed in Section 531.001,
1-26 Government Code.
1-27 (5) "Public health purpose" means a purpose that
1-28 relates to cancer, a birth defect, an infectious disease, a chronic
1-29 disease, environmental exposure, or newborn screening.
1-30 (a-1) Reports, records, and information obtained or
1-31 developed by the department under this chapter are confidential and
1-32 are not subject to disclosure under Chapter 552, Government Code,
1-33 are not subject to subpoena, and may not otherwise be released or
1-34 made public except as provided by this section.
1-35 (b) Notwithstanding other law, reports, records, and
1-36 information obtained or developed by the department under this
1-37 chapter may be disclosed:
1-38 (1) for purposes of diagnosis or follow-up authorized
1-39 under Section 33.014;
1-40 (2) with the consent of each identified individual or
1-41 an individual authorized to consent on behalf of an identified
1-42 child;
1-43 (3) as authorized by court order;
1-44 (4) to a medical examiner authorized to conduct an
1-45 autopsy on a child or an inquest on the death of a child; or
1-46 (5) to public health programs of the department for
1-47 public health research purposes, provided that the disclosure is
1-48 approved by:
1-49 (A) the commissioner or the commissioner's
1-50 designee; and
1-51 (B) an institutional review board or privacy
1-52 board of the department as authorized by the federal privacy
1-53 requirements adopted under the Health Insurance Portability and
1-54 Accountability Act of 1996 (Pub. L. No. 104-191) contained in 45
1-55 C.F.R. Part 160 and 45 C.F.R. Part 164, Subparts A and E.
1-56 (c) Notwithstanding other law, reports, records, and
1-57 information that do not identify a child or the family of a child
1-58 may be released without consent if the disclosure is for:
1-59 (1) statistical purposes;
1-60 (2) purposes related to obtaining or maintaining
1-61 federal certification, including related ~~approval, or~~ quality
1-62 assurance, for:
1-63 (A) the department's laboratory; or

2-1 (B) a public or private laboratory to perform
 2-2 newborn screening tests that are not part of inter-laboratory
 2-3 exchanges required for federal certification of the department's
 2-4 laboratory, provided that the disclosure is approved by the
 2-5 commissioner or the commissioner's designee;

2-6 (3) purposes relating to:
 2-7 (A) review or [7] quality assurance[~~, or~~
 2-8 ~~improvement~~] of the department's newborn screening under this
 2-9 chapter or the department's newborn screening program services
 2-10 under Subchapter C; or

2-11 (B) improvement of the department's newborn
 2-12 screening under this chapter or the department's newborn screening
 2-13 program services under Subchapter C, provided that the disclosure
 2-14 is approved by the commissioner or the commissioner's designee; or

2-15 (4) other [research purposes, provided that the
 2-16 disclosure is approved by an institutional review board or privacy
 2-17 board of the department; or

2-18 [~~5~~] quality assurance purposes related to public
 2-19 health testing equipment and supplies, provided that the disclosure
 2-20 is approved by:

2-21 (A) the commissioner or the commissioner's
 2-22 designee [assessment is performed by a person who is not a
 2-23 laboratory]; and

2-24 (B) [only newborn screening specimens are
 2-25 disclosed; and

2-26 [~~(C) the disclosure is approved by~~] an
 2-27 institutional review board or privacy board of the department.

2-28 (c-1) Notwithstanding other law, reports, records, and
 2-29 information that do not identify a child or the family of a child
 2-30 may be released for public health research purposes if:

2-31 (1) a parent of the child consents to the disclosure;
 2-32 and

2-33 (2) the disclosure is approved by:

2-34 (A) an institutional review board or privacy
 2-35 board of the department; and

2-36 (B) the commissioner or the commissioner's
 2-37 designee.

2-38 (e) If disclosure is approved by the commissioner or the
 2-39 commissioner's designee under Subsection (c)(4) or (c-1), the
 2-40 department shall post notice on the newborn screening web page on
 2-41 the department's Internet website that disclosure has been
 2-42 approved. The commissioner shall determine the form and content of
 2-43 the notice.

2-44 (f) In accordance with this section, the commissioner or the
 2-45 commissioner's designee:

2-46 (1) may approve disclosure of reports, records, or
 2-47 information obtained or developed under this chapter only for a
 2-48 public health purpose; and

2-49 (2) may not approve disclosure of reports, records, or
 2-50 information obtained or developed under this chapter for purposes
 2-51 related to forensic science or health insurance underwriting.

2-52 (g) An institutional review board or privacy board of the
 2-53 department that approves disclosure under this section must include
 2-54 at least three persons who are not affiliated with a health agency,
 2-55 one of whom must be a member of the public.

2-56 (h) The requirement that consent be obtained before certain
 2-57 disclosures of reports, records, or information may be made under
 2-58 this section does not affect the requirement that screening tests
 2-59 be performed under Section 33.011.

2-60 (i) If a parent of a child consents to disclosure under this
 2-61 section:

2-62 (1) a parent of the child may revoke the consent, in
 2-63 whole or in part, at any time; and

2-64 (2) the child may revoke the consent, in whole or in
 2-65 part, at any time on or after the date the child attains the age of
 2-66 majority.

2-67 SECTION 2. (a) Except as provided by Subsection (b) of
 2-68 this section, this Act takes effect immediately if it receives a
 2-69 vote of two-thirds of all the members elected to each house, as

3-1 provided by Section 39, Article III, Texas Constitution. If this
3-2 Act does not receive the vote necessary for immediate effect, this
3-3 Act takes effect September 1, 2011.

3-4 (b) Section 33.017(c-1), Health Safety Code, as added by
3-5 this Act, takes effect June 1, 2012.

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