By: Crownover, Zerwas, Coleman, et al.

H.B. No. 1672

Substitute the following for H.B. No. 1672:

By: Gonzales

C.S.H.B. No. 1672

A BILL TO BE ENTITLED

1 AN ACT

- 2 relating to newborn screening information.
- 3 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF TEXAS:
- 4 SECTION 1. Subchapter B, Chapter 33, Health and Safety
- 5 Code, is amended by adding Sections 33.0111 and 33.0112 to read as
- 6 follows:
- 7 Sec. 33.0111. DISCLOSURE. (a) The department shall develop
- 8 a disclosure statement that discloses to the parent, managing
- 9 conservator, or guardian of a newborn child subjected to screening
- 10 tests under Section 33.011 that:
- 11 (1) the department or a laboratory established or
- 12 approved by the department under Section 33.016 may retain for use
- 13 by the department or laboratory genetic material used to conduct
- 14 the newborn screening tests; and
- 15 (2) the parent, managing conservator, or guardian may
- 16 limit the use of the genetic material by providing to the department
- 17 in accordance with Section 33.0112 a written statement prohibiting
- 18 the department or laboratory from retaining the genetic material.
- 19 (b) At the time a newborn child is subjected to screening
- 20 tests under Section 33.011, the physician attending a newborn child
- 21 or the person attending the delivery of a newborn child that is not
- 22 attended by a physician shall provide the parent, managing
- 23 conservator, or guardian of a newborn child a copy of the written
- 24 disclosure statement developed by the department under this

- 1 section.
- 2 Sec. 33.0112. STATEMENT PROHIBITING RETENTION OF GENETIC
- 3 MATERIAL. (a) A parent, managing conservator, or guardian of a
- 4 newborn child may file with the department a written statement
- 5 prohibiting the department or a laboratory established or approved
- 6 by the department from retaining any genetic material related to
- 7 the newborn screening tests conducted under this subchapter.
- 8 (b) Not later than the 60th day after the department
- 9 receives the written statement, the department or laboratory shall
- 10 destroy the genetic material used in the screening tests.
- 11 SECTION 2. Subchapter B, Chapter 33, Health and Safety
- 12 Code, is amended by adding Section 33.017 to read as follows:
- Sec. 33.017. CONFIDENTIALITY. (a) Reports, records, and
- 14 information obtained or developed by the department under this
- 15 chapter are confidential and are not subject to disclosure under
- 16 Chapter 552, Government Code, are not subject to subpoena, and may
- 17 not otherwise be released or made public except as provided by this
- 18 section.
- 19 (b) Notwithstanding other law, reports, records, and
- 20 information obtained or developed by the department under this
- 21 chapter may be disclosed:
- 22 (1) for purposes of diagnosis or follow-up authorized
- 23 under Section 33.014;
- 24 (2) with the consent of each identified individual or
- 25 an individual authorized to consent on behalf of an identified
- 26 child;
- 27 (3) as authorized by court order;

(4) to a medical examiner authorized to conduct an 1 2 autopsy on a child or an inquest on the death of a child; or (5) to public health programs of the department for 3 public health research purposes provided that the disclosure is 4 5 approved by an institutional review board or privacy board of the department as authorized by the federal privacy requirements 6 7 adopted under the Health Insurance Portability and Accountability 8 Act of 1996 (Pub. L. No. 104-191) contained in 45 C.F.R. Part 160 and 45 C.F.R. Part 164, Subparts A and E. 9 (c) Notwithstanding other law, reports, records, and 10 information that do not identify a child or the family of a child 11 12 may be released without consent if the disclosure is for: (1) statistical purposes; 13 14 (2) purposes related to obtaining or maintaining 15 certification, approval, or quality assurance for the department's laboratory or a public or private laboratory to perform newborn 16 17 screening tests; (3) purposes relating to review, quality assurance, or 18 19 improvement of the department's newborn screening under this subchapter or the department's newborn screening program services 20 under Subchapter C; 21 22 (4) research purposes, provided that the disclosure is approved by an institutional review board or privacy board of the 23 24 department; or 25 (5) quality assurance related to equipment and 26 supplies, provided that:

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(A) the ass<u>essment is performed by a person who</u>

- 1 is not a laboratory;
- 2 (B) only newborn screening specimens are
- 3 disclosed; and
- 4 (C) the disclosure is approved by an
- 5 institutional review board or privacy board of the department.
- 6 (d) A state officer or employee, a department contractor, or
- 7 a department contractor's employee, officer, director, or
- 8 subcontractor may not be examined in a civil, criminal, special, or
- 9 other judicial or administrative proceeding as to the existence or
- 10 contents of records, reports, or information made confidential by
- 11 this section unless disclosure is authorized by this section.
- 12 SECTION 3. As soon as practicable after the effective date
- 13 of this Act, the Department of State Health Services shall develop
- 14 the disclosure statement required by Section 33.0111, Health and
- 15 Safety Code, as added by this Act. The department may modify an
- 16 existing form for use for purposes of that section.
- 17 SECTION 4. This Act takes effect immediately if it receives
- 18 a vote of two-thirds of all the members elected to each house, as
- 19 provided by Section 39, Article III, Texas Constitution. If this
- 20 Act does not receive the vote necessary for immediate effect, this
- 21 Act takes effect September 1, 2009.