## Texas

### Newborn Genetic Testing & Surveillance System

<table>
<thead>
<tr>
<th>State</th>
<th>Statute/Rule</th>
<th>Language Specific to Genetic Testing and Surveillance System</th>
<th>Exemption</th>
<th>Research Authority</th>
<th>Consent Required?</th>
<th>Dissent Allowed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>TX</td>
<td>STATUTE: T.S., Chapter 33, Sections 33.001 – 33.037 RULE: T.A.C. Title 25, Part 1, Chapter 37, Subchapter D, Rules 37.51 – 37.65</td>
<td>Sec. 33.002. DETECTION AND TREATMENT PROGRAM ESTABLISHED. (a) The department shall carry out a program to combat morbidity, including mental retardation, and mortality in persons who have phenylketonuria, other heritable diseases, or hypothyroidism. (b) The board shall adopt rules necessary to carry out the program, including a rule specifying other heritable diseases covered by this chapter.</td>
<td>Sec. 33.012. EXEMPTION. (a) Screening tests may not be administered to a newborn child whose parents, managing conservator, or guardian objects on the ground that the tests conflict with the religious tenets or practices of an organized church of which they are adherents.</td>
<td>Sec. 33.002. DETECTION AND TREATMENT PROGRAM ESTABLISHED …(c) The department shall establish and maintain a laboratory to: (1) conduct experiments, projects, and other activities necessary to develop screening or diagnostic tests for the early detection of phenylketonuria, other heritable diseases, and hypothyroidism; (2) develop ways and means or discover methods to be used to prevent or treat phenylketonuria, other heritable diseases, and hypothyroidism; and</td>
<td>NO</td>
<td>YES</td>
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**Sec. 33.011. TEST REQUIREMENT.**

(a) The physician attending a newborn child or the person attending the delivery of a newborn child that is not attended by a physician shall subject the child to screening tests approved by the department for phenylketonuria, other heritable diseases, hypothyroidism, and other disorders for which screening is required by the department.

(b) If a parent, managing conservator, or guardian objects to the screening tests, the physician or the person attending the newborn child that is not attended by a physician shall ensure that the objection of the parent, managing conservator, or guardian is entered into the medical record of the child. The parent, managing conservator, or guardian shall sign the entry. (3) serve other purposes considered necessary by the department to carry out the program.

**Sec. 33.015. REPORTS; RECORD KEEPING.**

(a) Each physician, health authority, or other individual who has the information of a confirmed case of a disorder for which a screening test is required that has been detected by a mechanism other than identification through a screening of a specimen by the department's diagnostic laboratory shall report the confirmed case to the department.

(b) If a parent, managing conservator, or guardian objects to the screening tests, the physician or the person attending the newborn child that is not attended by a physician shall ensure that the objection of the parent, managing conservator, or guardian is entered into the medical record of the child. The parent, managing conservator, or guardian shall sign the entry.

**Sec. 33.018 Confidentiality**

(a) In this section... (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, are not subject to subpoena, and may not otherwise be released or made public except as provided by this section.
(b) The department may collect data to derive incidence and prevalence rates of disorders covered by this chapter from the information on the specimen form submitted to the department for screening determinations. (c) The department shall maintain a roster of children born in this state who have been diagnosed as having one of the disorders for which the screening tests are required.

(d) The department may cooperate with other states in the development of a national roster of individuals who have been diagnosed as having one of the disorders for which the screening tests are required if:

(1) participation in the national roster encourages systematic follow-up in the participating states;

Sec. 33.013. LIMITATION ON LIABILITY. A physician, technician, or other person administering the screening tests required by this chapter is not liable or responsible because of the failure or refusal of a parent, managing conservator, or guardian to consent to the tests for which this chapter provides.

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

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

(6) for purposes relating to review or quality assurance of the department’s newborn screening…

(7) for purposes related to obtaining or maintaining federal certification, including related quality assurance, for the department’s laboratory…

(8) for purposes relating to improvement of the department’s newborn screening under this chapter or the department’s newborn screening program services under Subchapter C…
(2) incidence and prevalence information is made available to participating newborn screening programs in other states; and
(3) each participating newborn screening program subscribes to an agreement to protect the identity and diagnosis of the individuals whose names are included in the national roster. [emphasis added]

RULE §37.58 Follow-up and Record Keeping on Abnormal Screens
(a) The department shall maintain an active system of follow-up for suspected cases of each disorder for which screens are required.
(b) Health authorities, public health departments, public health districts, and the department's health service regions may provide follow-up and other needed assistance for individuals at risk from the disorders for which screens are required as requested by the department…

RULE §37.54. Exemption from Screens
A newborn may not be screened if the parent, managing conservator, or guardian objects to the screens because the screens conflict with the religious tenets or practices of the parent, managing conservator, or guardian.

(f) In accordance with this section, the commissioner or the commissioner’s designee:
(1) may approve disclosure of reports, records, or information obtained or developed under this chapter only for a public health purpose; and
(2) may not approve disclosure of reports, records, or information obtained or developed under this chapter for purposes related to forensic science or health insurance underwriting. …
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<td><strong>(e)</strong> Physicians or health care practitioners shall report to the department all confirmed cases of the disorders for which required screens are performed that have been detected by other mechanisms…</td>
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<td><strong>(g)</strong> The department may follow up with a confirmed case through periodic data collection from the physician or health care practitioner or parent, managing conservator, or guardian.</td>
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<td><strong>(h)</strong> The department shall maintain a registry of children born in Texas who have been diagnosed as having one of the disorders for which screens are required.</td>
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