

Candice B. Pierucci proposes the following substitute bill:

Newborn Infant Testing Privacy Amendments

2025 GENERAL SESSION

STATE OF UTAH

Chief Sponsor: Candice B. Pierucci

Senate Sponsor:

LONG TITLE

General Description:

This bill addresses newborn infant testing.

Highlighted Provisions:

This bill:

- requires the Department of Health and Human Services (department) to publish a privacy consent form pertaining to newborn infant testing;

- requires that the privacy consent form be provided to a newborn infant's parent or guardian prior to conducting newborn infant testing;

- provides for giving a parent or guardian the option to consent to the department's retention policy for biological samples or genetic data collected through newborn infant testing;

- requires the department to destroy a biological sample or any genetic data collected through newborn infant testing; and

- makes technical changes.

Money Appropriated in this Bill:

None

Other Special Clauses:

None

Utah Code Sections Affected:

AMENDS:

26B-4-319, as renumbered and amended by Laws of Utah 2023, Chapter 307

Be it enacted by the Legislature of the state of Utah:

Section 1. Section **26B-4-319** is amended to read:

26B-4-319 . Testing of newborn infants.

(1)(a) Except in the case where parents object on the grounds that they are members of a specified, well-recognized religious organization whose teachings are contrary to the tests required by this section, a newborn infant shall be tested for:

~~[(a)]~~ (i) phenylketonuria (PKU);

~~[(b)]~~ (ii) other heritable disorders which may result in an intellectual or physical disability or death and for which:

~~[(i)]~~ (A) a preventive measure or treatment is available; and

~~[(ii)]~~ (B) there exists a reliable laboratory diagnostic test method;

~~[(c)]~~ (iii)~~[(i)]~~ (A) an infant born in a hospital with 100 or more live births annually, hearing loss; and

~~[(ii)]~~ (B) an infant born in a setting other than a hospital with 100 or more live births annually, hearing loss; and

~~[(d)]~~ (iv) critical congenital heart defects using pulse oximetry.

(b)(i) Prior to conducting a newborn infant test under this section, a copy of the privacy consent form described in Subsection (5) shall be provided to the newborn infant's parent or guardian.

(ii) The department may retain, in accordance with the department's retention policy, a biological sample and any genetic data, as those terms are defined in Section 13-60-102, collected under this section, only if a parent or guardian consents to the retention policy on the privacy consent form.

(c) A biological sample and any genetic data collected under this section shall be destroyed:

(i) according to the department's retention policy; or

(ii) if the newborn infant's parent or guardian does not consent to the department's retention policy, upon completion of the newborn infant's testing under this section.

(2) In accordance with Section 26B-1-209, the department may charge fees for:

(a) materials supplied by the department to conduct tests required under Subsection (1);

(b) tests required under Subsection (1) conducted by the department;

(c) laboratory analyses by the department of tests conducted under Subsection (1); and

(d) the administrative cost of follow-up contacts with the parents or guardians of tested infants.

(3) Tests for hearing loss described in Subsection (1) shall be based on one or more methods approved by the Newborn Hearing Screening Committee created in Section

26B-1-432, including:

- (a) auditory brainstem response;
- (b) automated auditory brainstem response; and
- (c) evoked otoacoustic emissions.

(4) Results of tests for hearing loss described in Subsection (1) shall be reported to:

- (a) the department; and
- (b) when results of tests for hearing loss under Subsection (1) suggest that additional diagnostic procedures or medical interventions are necessary:
 - (i) a parent or guardian of the infant;
 - (ii) an early intervention program administered by the department in accordance with Part C of the Individuals with Disabilities Education Act, 20 U.S.C. Sec. 1431 et seq.; and
 - (iii) the Utah Schools for the Deaf and the Blind, created in Section 53E-8-201.

(5) The department shall publish a privacy consent form containing:

- (a) relevant facts and information about:
 - (i) the purposes for which the department retains biological samples or any genetic data obtained through newborn infant testing; and
 - (ii) the department's retention policy for biological samples or any genetic data obtained through newborn infant testing; and
- (b) the option for a parent or guardian to indicate consent to the department's retention policy.

Section 2. **Effective date.**

This bill takes effect on May 7, 2025.