

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: Heidi Balderree

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.

- 29 (1)(a) Except in the case where parents object on the grounds that they are members of a
30 specified, well-recognized religious organization whose teachings are contrary to the
31 tests required by this section, a newborn infant shall be tested for:
- 32 [~~(a)~~] (i) phenylketonuria (PKU);
33 [~~(b)~~] (ii) other heritable disorders which may result in an intellectual or physical
34 disability or death and for which:
35 [~~(i)~~] (A) a preventive measure or treatment is available; and
36 [~~(ii)~~] (B) there exists a reliable laboratory diagnostic test method;
37 [~~(c)~~] (iii)[~~(i)~~] (A) an infant born in a hospital with 100 or more live births annually,
38 hearing loss; and
39 [~~(ii)~~] (B) an infant born in a setting other than a hospital with 100 or more live
40 births annually, hearing loss; and
41 [~~(d)~~] (iv) critical congenital heart defects using pulse oximetry.
- 42 (b)(i) Prior to conducting a newborn infant test under this section, a copy of the
43 privacy consent form described in Subsection (5) shall be provided to the newborn
44 infant's parent or guardian.
- 45 (ii) The department may retain, in accordance with the department's retention policy,
46 a biological sample and any genetic data, as those terms are defined in Section
47 13-60-102, collected under this section, only if a parent or guardian consents to
48 the retention policy on the privacy consent form.
- 49 (c) A biological sample and any genetic data collected under this section shall be
50 destroyed:
- 51 (i) according to the department's retention policy; or
52 (ii) if the newborn infant's parent or guardian does not consent to the department's
53 retention policy, upon completion of the newborn infant's testing under this
54 section.
- 55 (2) In accordance with Section 26B-1-209, the department may charge fees for:
- 56 (a) materials supplied by the department to conduct tests required under Subsection (1);
57 (b) tests required under Subsection (1) conducted by the department;
58 (c) laboratory analyses by the department of tests conducted under Subsection (1); and
59 (d) the administrative cost of follow-up contacts with the parents or guardians of tested
60 infants.
- 61 (3) Tests for hearing loss described in Subsection (1) shall be based on one or more
62 methods approved by the Newborn Hearing Screening Committee created in Section

- 63 26B-1-432, including:
- 64 (a) auditory brainstem response;
- 65 (b) automated auditory brainstem response; and
- 66 (c) evoked otoacoustic emissions.
- 67 (4) Results of tests for hearing loss described in Subsection (1) shall be reported to:
- 68 (a) the department; and
- 69 (b) when results of tests for hearing loss under Subsection (1) suggest that additional
- 70 diagnostic procedures or medical interventions are necessary:
- 71 (i) a parent or guardian of the infant;
- 72 (ii) an early intervention program administered by the department in accordance with
- 73 Part C of the Individuals with Disabilities Education Act, 20 U.S.C. Sec. 1431 et
- 74 seq.; and
- 75 (iii) the Utah Schools for the Deaf and the Blind, created in Section 53E-8-201.
- 76 (5) The department shall publish a privacy consent form containing:
- 77 (a) relevant facts and information about:
- 78 (i) the purposes for which the department retains biological samples or any genetic
- 79 data obtained through newborn infant testing; and
- 80 (ii) the department's retention policy for biological samples or any genetic data
- 81 obtained through newborn infant testing; and
- 82 (b) the option for a parent or guardian to indicate consent to the department's retention
- 83 policy.
- 84 Section 2. **Effective date.**
- 85 This bill takes effect on May 7, 2025.