

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 a newborn infant heelstick screen;

▸ makes hearing loss a required newborn infant test, regardless of the number of annual births that occur at the hospital or setting where the infant was born;

▸ 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:

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

30 **26B-4-319 . Testing of newborn infants.**

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

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

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

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

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

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

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

43 (iii) hearing loss; and

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

45 (b)(i) Prior to conducting newborn infant testing under this section, information shall
46 be provided to the newborn infant's parent or guardian explaining relevant facts
47 and information about newborn infant testing and sample storage under this
48 section.

49 (ii) Prior to conducting a newborn infant heelstick screen under this section, a copy of
50 the privacy consent form described in Subsection (5) shall be provided to the
51 newborn infant's parent or guardian.

52 (iii) The department may retain, in accordance with the department's retention policy,
53 a biological sample and any genetic data, as those terms are defined in Section
54 13-60-102, collected under this section, only if a parent or guardian consents to
55 the retention policy on the privacy consent form.

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

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

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

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

- 63 (a) materials supplied by the department to conduct tests required under Subsection (1);
64 (b) tests required under Subsection (1) conducted by the department;
65 (c) laboratory analyses by the department of tests conducted under Subsection (1); and
66 (d) the administrative cost of follow-up contacts with the parents or guardians of tested
67 infants.
- 68 (3) Tests for hearing loss described in Subsection (1) shall be based on one or more
69 methods approved by the Newborn Hearing Screening Committee created in Section
70 26B-1-432, including:
- 71 (a) auditory brainstem response;
72 (b) automated auditory brainstem response; and
73 (c) evoked otoacoustic emissions.
- 74 (4) Results of tests for hearing loss described in Subsection (1) shall be reported to:
- 75 (a) the department; and
76 (b) when results of tests for hearing loss under Subsection (1) suggest that additional
77 diagnostic procedures or medical interventions are necessary:
78 (i) a parent or guardian of the infant;
79 (ii) an early intervention program administered by the department in accordance with
80 Part C of the Individuals with Disabilities Education Act, 20 U.S.C. Sec. 1431 et
81 seq.; and
82 (iii) the Utah Schools for the Deaf and the Blind, created in Section 53E-8-201.
- 83 (5) The department shall publish a privacy consent form containing:
- 84 (a) relevant facts and information about:
- 85 (i) the purposes for which the department retains biological samples or any genetic
86 data obtained through newborn infant testing; and
87 (ii) the department's retention policy for biological samples or any genetic data
88 obtained through newborn infant testing; and
- 89 (b) the option for a parent or guardian to indicate consent to the department's retention
90 policy.

91 Section 2. **Effective date.**

92 This bill takes effect on May 7, 2025.