

1 **Newborn Infant Testing Amendments**

2025 GENERAL SESSION

STATE OF UTAH

Chief Sponsor: Candice B. Pierucci

Senate Sponsor:

3 **LONG TITLE**

4 **General Description:**

5 This bill addresses newborn infant health testing.

6 **Highlighted Provisions:**

7 This bill:

8 ▶ requires that an informational form, including an option to opt out of testing, be provided
9 to a newborn infant's parent or guardian at least 24 hours prior to administering newborn
10 infant health testing;

11 ▶ prohibits newborn infant health testing for certain tests to which a parent or guardian opts
12 out on the form;

13 ▶ limits the use and sharing of a biological sample collected in connection with newborn
14 infant health testing; and

15 ▶ requires that a biological sample collected in connection with newborn infant health
16 testing is destroyed within 90 days.

17 **Money Appropriated in this Bill:**

18 None

19 **Other Special Clauses:**

20 None

21 **Utah Code Sections Affected:**

22 AMENDS:

23 **26B-4-319**, as renumbered and amended by Laws of Utah 2023, Chapter 307

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

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

27 **26B-4-319 . Testing of newborn infants.**

28 (1)(a) [~~Except in the case where parents object on the grounds that they are members of~~
29 ~~a specified, well-recognized religious organization whose teachings are contrary to~~
30 ~~the tests required by this section]~~ Subject to Subsection (1)(c), a newborn infant shall

- 31 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) At least 24 hours prior to a test under Subsection (1)(a), a copy of the form
- 43 published under Subsection (5) shall be provided to a newborn infant's parent or
- 44 guardian.
- 45 (ii) A test under Subsections (1)(a)(i) through (1)(a)(iv) may not occur if a parent or
- 46 guardian has opted out of the test on the form.
- 47 (c)(i) A biological sample and any genetic data, as those terms are defined in Section
- 48 13-60-102, collected in connection with testing under Subsection (1)(a):
- 49 (A) may be used and shared only as provided in this section; and
- 50 (B) except as provided in Subsection (1)(c)(ii), shall be destroyed no later than 90
- 51 days after the date on which the biological sample is collected.
- 52 (ii) Subsection (1)(c)(i)(B) does not apply to a biological sample and any genetic data
- 53 that is medically relevant to the treatment of a condition of the newborn infant
- 54 from whom the sample or any genetic data derives.
- 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 form containing:
- 77 (a) relevant facts and information about newborn infant testing under this section; and
78 (b) the option for a parent or guardian to opt out of newborn infant testing.
- 79 Section 2. **Effective date.**
- 80 This bill takes effect on May 7, 2025.