

Newborn Infant Testing Amendments

2025 GENERAL SESSION

STATE OF UTAH

Chief Sponsor: Candice B. Pierucci

Senate Sponsor:

LONG TITLE**General Description:**

This bill addresses newborn infant health testing.

Highlighted Provisions:

This bill:

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

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

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

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

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]~~ 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;

(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 form containing:

(a) relevant facts and information about newborn infant testing under this section; and

(b) the option for a parent or guardian to opt out of newborn infant testing.

Section 2. **Effective date.**

This bill takes effect on May 7, 2025.