

HB0363S02 compared with HB0363S01

~~{Omitted text}~~ shows text that was in HB0363S01 but was omitted in HB0363S02

inserted text shows text that was not in HB0363S01 but was inserted into HB0363S02

DISCLAIMER: This document is provided to assist you in your comparison of the two bills. Sometimes this automated comparison will NOT be completely accurate. Therefore, you need to read the actual bills. This automatically generated document could contain inaccuracies caused by: limitations of the compare program; bad input data; or other causes.

1 Newborn Infant Testing Privacy Amendments

2025 GENERAL SESSION

STATE OF UTAH

Chief Sponsor: Candice B. Pierucci

Senate Sponsor: Heidi Balderree

2 LONG TITLE

3 General Description:

4 This bill addresses newborn infant testing.

5 Highlighted Provisions:

6 This bill:

7

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

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- 10 requires that the privacy consent form be provided to a newborn infant's parent or guardian prior to conducting a newborn infant ~~{testing}~~ heelstick screen;

11

- 12 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;

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- 14 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;

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

17

- 18 makes technical changes.

HB0363S01

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20 **Money Appropriated in this Bill:**

21 None

22 **Other Special Clauses:**

23 None

24 AMENDS:

25 **26B-4-319** , as renumbered and amended by Laws of Utah 2023, Chapter 307 , as renumbered and
26 amended by Laws of Utah 2023, Chapter 307

27

28 *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.** <compare mode="add">(Compare Error)</
31 **compare>**

29 (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:

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

33 [~~(b)~~] (ii) other heritable disorders which may result in an intellectual or physical 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 [~~(e)~~] (iii)

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

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

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

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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.

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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.

49 A biological sample and any genetic data collected under this section shall be destroyed:
51 according to the department's retention policy; or
52 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.

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 infants.

61 (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:

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 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 Part C of the
Individuals with Disabilities Education Act, 20 U.S.C. Sec. 1431 et seq.; and

75 (iii) the Utah Schools for the Deaf and the Blind, created in Section 53E-8-201.

76 The department shall publish a privacy consent form containing:

77 relevant facts and information about:

78 the purposes for which the department retains biological samples or any genetic data obtained through
newborn infant testing; and

80 the department's retention policy for biological samples or any genetic data obtained through newborn
infant testing; and

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82 the option for a parent or guardian to indicate consent to the department's retention policy.

91 Section 2. **Effective date.**

This bill takes effect on May 7, 2025.

3-3-25 12:39 PM