

HB0363S02 compared with HB0363

~~{Omitted text}~~ shows text that was in HB0363 but was omitted in HB0363S02
inserted text shows text that was not in HB0363 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
3 **LONG TITLE**

4 **General Description:**

5 This bill addresses newborn infant ~~{health}~~ testing.

6 **Highlighted Provisions:**

7 This bill:

- 8
 - ▶ requires the Department of Health and Human Services (department) to publish a privacy consent form pertaining to newborn infant testing;
 - 8 ▶ requires that ~~{an informational form, including an option to opt out of testing,}~~ the privacy consent form be provided to a newborn infant's parent or guardian ~~{at least 24 hours}~~ prior to ~~{administering}~~ conducting a newborn infant ~~{health testing}~~ heelstick screen;
 - 11 ▶ ~~{prohibits}~~ makes hearing loss a required newborn infant ~~{health testing for certain tests to which a parent}~~ test, regardless of the number of annual births that occur at the hospital or ~~{guardian opts out on}~~ setting where the ~~{form}~~ infant was born;
 - 13 ▶ ~~{limits}~~ provides for giving a parent or guardian the option to consent to the ~~{use and sharing of a biological sample}~~ department's retention policy for biological samples or genetic data collected ~~{in connection with}~~ through newborn infant ~~{health}~~ testing; ~~{and}~~

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15 ▸ requires ~~{that}~~ the department to destroy a biological sample or any genetic data collected ~~{in~~
16 connection with} through newborn infant ~~{health}~~ testing ~~{is destroyed within 90 days.}~~ ; and

19 ▸ makes technical changes.

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

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

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

29 **26B-4-319. Testing of newborn infants.** ~~<compare mode="add">(Compare Error)</~~

30 **compare>**

31 (1)

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

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

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

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

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

40 ~~[(e)] (iii)~~

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

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

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

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At least 24 hours prior to a test under Subsection (1)(a), a copy of the form published under Subsection (5) shall be provided to a newborn infant's parent or guardian.

45 A test under Subsections (1)(a)(i) through (1)(a)(iv) may not occur if a parent or guardian has opted out
47 of the test on the form.

A biological sample and any genetic data, as those terms are defined in Section 13-60-102, collected in
49 connection with testing under Subsection (1)(a):

49 may be used and shared only as provided in this section; and

50 except as provided in Subsection (1)(c)(ii), shall be destroyed no later than 90 days after the date
52 on which the biological sample is collected.

52 Subsection (1)(c)(i)(B) does not apply to a biological sample and any genetic data that is medically
55 relevant to the treatment of a condition of the newborn infant from whom the sample or any genetic
56 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 infants.

61 (3) Tests for hearing loss described in Subsection (1) shall be based on one or more methods approved
64 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
71 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
75 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.

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76 The department shall publish a form containing:
77 relevant facts and information about newborn infant testing under this section; and
78 the option for a parent or guardian to opt out of newborn infant testing.

91 Section 2. **Effective date.**

This bill takes effect on May 7, 2025.

3-3-25 12:39 PM