

HB0363S01 compared with HB0363

~~{Omitted text}~~ shows text that was in HB0363 but was omitted in HB0363S01

inserted text shows text that was not in HB0363 but was inserted into HB0363S01

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.

Newborn Infant Testing Privacy 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 the Department of Health and Human Services (department) to publish a privacy consent form pertaining to newborn infant testing;

▶ requires that ~~{an informational-}~~ the privacy consent 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-}~~ conducting newborn infant ~~{health-}~~ testing;

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

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

17 ▶ makes technical changes.

18 Money Appropriated in this Bill:

19 None

20 None

23 AMENDS:

24 **26B-4-319** , as renumbered and amended by Laws of Utah 2023, Chapter 307 , as renumbered and amended by Laws of Utah 2023, Chapter 307

25

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

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

28 **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 a specified, well-recognized religious organization whose teachings are contrary to the tests required by this section{}}~~ Subject to Subsection (1)(e), 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 ~~{(c)}~~ (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.

42 (b)

 . (i) ~~{At least 24 hours prior}~~ Prior to ~~{a}~~ conducting a newborn infant test under ~~{Subsection (1)(a)}~~ this section, a copy of the privacy consent form ~~{published under}~~ described in Subsection (5) shall be provided to ~~{a}~~ the newborn infant's parent or guardian.

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- 45 ~~{(ii) {A test under Subsections (1)(a)(i) through (1)(a)(iv) may not occur if a parent or guardian has~~
~~opted out of the test on the form.}}~~
- 47 ~~{(e) }~~
- . ~~{(f) (ii) {A} 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
~~{in connection with testing under Subsection (1)(a):} under this section, only if a parent or guardian~~
~~consents to the retention policy on the privacy consent form.~~
- 49 ~~{(A) {may be used and shared only as provided in this section; and} }~~
- 50 ~~{(B) {except as provided in Subsection (1)(e)(ii), shall be destroyed no later than 90 days after the~~
date on which the biological sample is collected.}}
- 52 ~~{(ii) (c) {Subsection (1)(e)(i)(B) does not apply to a} A biological sample and any genetic data {that~~
is medically relevant to the treatment of a condition of the newborn infant from whom the sample or
~~any genetic data derives.} collected under this section shall be destroyed:~~
- 51 ~~(i) according to the department's retention policy; or~~
- 52 ~~(ii) 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;

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- 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 (5) The department shall publish a privacy consent form containing:
- 77 (a) relevant facts and information about {~~newborn infant testing under this section; and~~} :
- 78 (i) the purposes for which the department retains biological samples or any genetic data obtained
through newborn infant testing; and
- 80 (ii) the department's retention policy for biological samples or any genetic data obtained through
newborn infant testing; and
- 78 (b) the option for a parent or guardian to {~~opt out of newborn infant testing~~} indicate consent to the
department's retention policy.

84 Section 2. **Effective date.**

This bill takes effect on May 7, 2025.

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