

David P. Hinkins proposes the following substitute bill:

Newborn Testing Amendments

2025 GENERAL SESSION

STATE OF UTAH

Chief Sponsor: David P. Hinkins

House Sponsor:

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3 **LONG TITLE**

4 **General Description:**

5 This bill amends provisions related to newborn screening.

6 **Highlighted Provisions:**

7 This bill:

8 ▶ requires the Department of Health and Human Services to screen newborns for pyruvate
9 dehydrogenase complex deficiency;

10 ▶ amends provisions related to hearing loss testing; and

11 ▶ makes technical changes.

12 **Money Appropriated in this Bill:**

13 None

14 **Other Special Clauses:**

15 None

16 **Utah Code Sections Affected:**

17 AMENDS:

18 **26B-4-319**, as renumbered and amended by Laws of Utah 2023, Chapter 307

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

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

22 **26B-4-319 . Testing of newborn infants.**

23 (1) Except in the case where parents object on the grounds that they are members of a
24 specified, well-recognized religious organization whose teachings are contrary to the
25 tests required by this section, a newborn infant shall be tested for:

26 (a) phenylketonuria (PKU);

27 (b) pyruvate dehydrogenase complex deficiency (PDCD) if there is:

28 (i) a preventative measure or treatment available; and

29 (ii) a reliable laboratory diagnostic test method;

- 30 ~~[(b)]~~ (c) other heritable disorders which may result in an intellectual or physical disability
 31 or death and for which:
 32 (i) a preventive measure or treatment is available; and
 33 (ii) there exists a reliable laboratory diagnostic test method;
 34 (d) hearing loss; and
 35 ~~[(e)(i) an infant born in a hospital with 100 or more live births annually, hearing~~
 36 ~~loss; and]~~
 37 ~~[(ii) an infant born in a setting other than a hospital with 100 or more live births~~
 38 ~~annually, hearing loss; and]~~
 39 ~~[(d)]~~ (e) critical congenital heart defects using pulse oximetry.
- 40 (2) In accordance with Section 26B-1-209, the department may charge fees for:
 41 (a) materials supplied by the department to conduct tests required under Subsection (1);
 42 (b) tests required under Subsection (1) conducted by the department;
 43 (c) laboratory analyses by the department of tests conducted under Subsection (1); and
 44 (d) the administrative cost of follow-up contacts with the parents or guardians of tested
 45 infants.
- 46 (3) Tests for hearing loss described in Subsection (1) shall be based on one or more
 47 methods approved by the Newborn Hearing Screening Committee created in Section
 48 26B-1-432, including:
 49 (a) auditory brainstem response;
 50 (b) automated auditory brainstem response; and
 51 (c) evoked otoacoustic emissions.
- 52 (4) Results of tests for hearing loss described in Subsection (1) shall be reported to:
 53 (a) the department; and
 54 (b) when results of tests for hearing loss under Subsection (1) suggest that additional
 55 diagnostic procedures or medical interventions are necessary:
 56 (i) a parent or guardian of the infant;
 57 (ii) an early intervention program administered by the department in accordance with
 58 Part C of the Individuals with Disabilities Education Act, 20 U.S.C. Sec. 1431 et
 59 seq.; and
 60 (iii) the Utah Schools for the Deaf and the Blind, created in Section 53E-8-201.

61 Section 2. **Effective Date.**

62 This bill takes effect on May 7, 2025.