

Newborn Testing Amendments
2025 GENERAL SESSION
STATE OF UTAH
Chief Sponsor: David P. Hinkins

LONG TITLE

General Description:

This bill amends provisions related to newborn screening.

Highlighted Provisions:

This bill:

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

▸ makes technical changes.

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) 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:

(a) phenylketonuria (PKU);

(b) pyruvate dehydrogenase complex deficiency (PDCD);

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

(i) a preventive measure or treatment is available; and

(ii) there exists a reliable laboratory diagnostic test method;

(d) hearing loss if the infant was born in any setting, including a hospital, where 100 or

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

59 **Section 2. Effective Date.**

60 This bill takes effect on May 7, 2025.