

1 **NEWBORN SCREENING FOR CRITICAL CONGENITAL**

2 **HEART DEFECTS**

3 2013 GENERAL SESSION

4 STATE OF UTAH

5 **Chief Sponsor: Paul Ray**

6 Senate Sponsor: Ralph Okerlund

8 **LONG TITLE**

9 **General Description:**

10 This bill amends the Utah Health Code.

11 **Highlighted Provisions:**

12 This bill:

- 13 ▶ amends newborn testing requirements to include pulse oximetry for identification of
- 14 critical congenital heart defects;
- 15 ▶ requires the Department of Health to conduct a pilot program to determine the most
- 16 appropriate methods to implement pulse oximetry screening; and
- 17 ▶ makes technical changes.

18 **Money Appropriated in this Bill:**

19 None

20 **Other Special Clauses:**

21 None

22 **Utah Code Sections Affected:**

23 AMENDS:

24 **26-10-6**, as last amended by Laws of Utah 2011, Chapter 366

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

27 Section 1. Section **26-10-6** is amended to read:

28 **26-10-6. Testing of newborn infants.**

29 (1) Except in the case where parents object on the grounds that they are members of a

30 specified, well-recognized religious organization whose teachings are contrary to the tests
31 required by this section, each newborn infant shall be tested for:

- 32 (a) phenylketonuria (PKU);
- 33 (b) other [~~metabolic diseases~~] heritable disorders which may result in an intellectual or
34 physical disability or [~~brain damage~~] death and for which:

- 35 (i) a preventive measure or treatment is available; and
- 36 (ii) there exists a reliable laboratory diagnostic test method; [~~and~~]

37 (c) (i) [~~beginning July 1, 1998, for~~] an infant born in a hospital with 100 or more live
38 births annually, hearing loss; and

39 (ii) [~~beginning July 1, 1999, for~~] an infant born in a setting other than a hospital with
40 100 or more live births annually, hearing loss[-]; and

41 (d) beginning October 1, 2014, critical congenital heart defects using pulse oximetry.

42 (2) In accordance with Section 26-1-6, the department may charge fees for:

- 43 (a) materials supplied by the department to conduct tests required under Subsection (1);
- 44 (b) tests required under Subsection (1) conducted by the department;
- 45 (c) laboratory analyses by the department of tests conducted under Subsection (1); and
- 46 (d) the administrative cost of follow-up contacts with the parents or guardians of tested
47 infants.

48 (3) Tests for hearing loss under Subsection (1) shall be based on one or more methods
49 approved by the Newborn Hearing Screening Committee, including:

- 50 (a) auditory brainstem response;
- 51 (b) automated auditory brainstem response; and
- 52 (c) evoked otoacoustic emissions.

53 (4) Results of tests for hearing loss under Subsection (1) shall be reported to:

- 54 (a) parents when results of tests for hearing loss under Subsection (1) suggest that
55 additional diagnostic procedures or medical interventions are necessary; and
- 56 (b) the department.

57 (5) (a) There is established the Newborn Hearing Screening Committee.

- 58 (b) The committee shall advise the department on:
- 59 (i) the validity and cost of newborn infant hearing loss testing procedures; and
- 60 (ii) rules promulgated by the department to implement this section.
- 61 (c) The committee shall be composed of at least 11 members appointed by the
- 62 executive director, including:
- 63 (i) one representative of the health insurance industry;
- 64 (ii) one pediatrician;
- 65 (iii) one family practitioner;
- 66 (iv) one ear, nose, and throat specialist nominated by the Utah Medical Association;
- 67 (v) two audiologists nominated by the Utah Speech-Language-Hearing Association;
- 68 (vi) one representative of hospital neonatal nurseries;
- 69 (vii) one representative of the Early Intervention Baby Watch Program administered by
- 70 the department;
- 71 (viii) one public health nurse;
- 72 (ix) one consumer; and
- 73 (x) the executive director or his designee.
- 74 (d) Of the initial members of the committee, the executive director shall appoint as
- 75 nearly as possible half to two-year terms and half to four-year terms. Thereafter, appointments
- 76 shall be for four-year terms except:
- 77 (i) for those members who have been appointed to complete an unexpired term; and
- 78 (ii) as necessary to ensure that as nearly as possible the terms of half the appointments
- 79 expire every two years.
- 80 (e) A majority of the members constitute a quorum and a vote of the majority of the
- 81 members present constitutes an action of the committee.
- 82 (f) The committee shall appoint a chairman from its membership.
- 83 (g) The committee shall meet at least quarterly.
- 84 (h) A member may not receive compensation or benefits for the member's service, but
- 85 may receive per diem and travel expenses in accordance with:

- 86 (i) Section 63A-3-106;
- 87 (ii) Section 63A-3-107; and
- 88 (iii) rules made by the Division of Finance pursuant to Sections 63A-3-106 and
- 89 63A-3-107.

90 (i) The department shall provide staff for the committee.

91 (6) Prior to implementing the test required by Subsection (1)(d), the department shall
92 conduct a pilot program for testing newborns for critical congenital heart defects using pulse
93 oximetry. The pilot program shall include the development of:

94 (a) appropriate oxygen saturation levels that would indicate a need for further medical
95 follow-up; and

96 (b) the best methods for implementing the pulse oximetry screening in newborn care
97 units.