A BILL FOR AN ACT

RELATING TO NEWBORN SCREENING.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF HAWAII:

Traditionally, newborn screening involves blood 1 SECTION 1. collection from a heelstick and the use of biochemical and 2 molecular testing to screen for disorders. Results of this type 3 of newborn screening are most often available only after the 4 newborn's discharge home. In the late 1990s, the first type of 5 point of care newborn screening was introduced. In newborn 6 screening, the newborn is screened at an institution caring for 7 the newborn infant before discharge but follow-up additional 8 screening and possible diagnostic tests are scheduled after 9 discharge. Now a more intensive type of point of care newborn 10 screening is being introduced in which the newborn is screened 11 at an institution caring for the newborn infant before discharge 12 and if the newborn has a positive result, diagnostic tests are 13 administered before the newborn is discharged or arrangements 14 are made for transfer of the newborn to an institution that can 15 administer the diagnostic tests before the newborn is discharged 16 17 home.



Page 2

H.B. NO. ⁹⁰⁵ H.D. 1

The purpose of this Act is to establish point of care 1 newborn screening and authorize administrative rulemaking for 2 its implementation. 3 SECTION 2. Chapter 321, Hawaii Revised Statutes, is 4 amended by adding a new part to be appropriately designated and 5 to read as follows: 6 "PART . POINT OF CARE NEWBORN SCREENING 7 §321-A Definitions. For the purposes of this part: 8 "Department" means the department of health. 9 "Point of care newborn screening" means newborn infant 10 screening for diseases and conditions specified by the 11 department and administered at the institution caring for the 12 newborn infant, followed by diagnostic testing at the 13 institution, or at a health facility to which the infant is 14 transferred when a positive screening result is found, to 15 determine the cause of the positive screening result before the 16 newborn is discharged home. 17 "Positive screening result" means a newborn screening 18 result that is outside the normal range of screening results for 19 20 a newborn.



\$321-B Point of care newborn screening. (a) The
 department shall specify diseases and conditions covered by
 point of care newborn screening.

4 (b) The department shall specify policies and procedures
5 for administration of point of care newborn screening to be
6 administered by institutions caring for newborn infants to best
7 prevent newborn mortality and morbidity within the State.

(c) The person in charge of each institution caring for 8 newborn infants and the responsible physician attending the 9 birth of a newborn or the person assisting the birth of a 10 newborn not attended by a physician, shall ensure that every 11 newborn infant in the person's care be tested for the diseases 12 and conditions for point of care newborn screening specified by 13 the department; provided that this section shall not apply if 14 the parents, guardians, or other persons having custody or 15 control of the child object thereto on the grounds that the 16 tests conflict with their religious tenets and beliefs and 17 written objection is made a part of the newborn infant's medical 18 19 record.

20 (d) The department shall adopt rules pursuant to chapter
21 91 necessary for the purposes of this section, including:



Page 3

1	(1)	Specifying diseases and conditions for point of care
2		newborn screening;
3	(2)	Establishing policies and procedures for
4		administration of point of care newborn screening
5		tests;
6	(3)	Providing for quality and cost control of point of
7		care newborn screening tests;
8	(4)	Providing for retention of records and related data;
9	(5)	Tracking completion and results of point of care
10		newborn screening;
11	(6)	Formulating guidelines for care, treatment, and follow
12		up for newborn infants with positive test results;
13	(7)	Providing education for parents and healthcare
14		providers about the availability and purposes of point
15		of care newborn screening; and
16	(8)	Maintaining the confidentiality of newborns and
17		families.
18	(e)	The director of health shall submit an annual report
19	to the legislature twenty days prior to the convening of each	
20	regular session, identifying all expenditures made from the	
21	newborn metabolic screening special fund for the department's	
22	point of care newborn screening activities."	



SECTION 3. Section 321-291, Hawaii Revised Statutes, is 1 amended by amending subsection (d) to read as follows: 2 There is created in the treasury of the State the 3 "(d) newborn metabolic screening special fund. All moneys for 4 newborn metabolic screening services and point of care newborn 5 screening services collected under this chapter shall be 6 deposited in the newborn metabolic screening special fund to be 7 used for the payment of its lawful operating expenditures, 8 including but not limited to laboratory testing, follow-up 9 testing, educational materials, continuing education, quality 10 assurance, equipment, and indirect costs [-] for newborn 11 metabolic screening and for point of care newborn screening." 12 SECTION 4. Statutory material to be repealed is bracketed 13 and stricken. New statutory material is underscored. 14 SECTION 5. This Act, upon its approval, shall take effect 15 on July 1, 2050. 16



Report Title:

Point of Care Newborn Screening

Description:

Authorizes the Department of Health to implement point of care newborn screening, and amends section 321-291, HRS, concerning the newborn metabolic screening special fund. Effective July 1, 2050. (HB905 HD1)

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