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Date: (Filing No. H-)

HEALTH AND HUMAN SERVICES

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**STATE OF MAINE
HOUSE OF REPRESENTATIVES
126TH LEGISLATURE
FIRST REGULAR SESSION**

COMMITTEE AMENDMENT “ ” to H.P. 310, L.D. 460, Bill, “An Act To Protect Newborn Infants by Requiring Birthing Facilities To Screen for Congenital Heart Disease Using Pulse Oximetry”

Amend the bill by striking out the title and substituting the following:

'An Act To Protect Newborn Infants from Critical Congenital Heart Disease'

Amend the bill by striking out everything after the title and before the summary and inserting the following:

Emergency preamble. Whereas, acts and resolves of the Legislature do not become effective until 90 days after adjournment unless enacted as emergencies; and

Whereas, according to the United States Department of Health and Human Services' Secretary's Advisory Committee on Heritable Disorders in Newborns and Children, congenital heart disease affects 7 to 9 of every 1,000 children born in the United States and Europe; and

Whereas, the federal Centers for Disease Control and Prevention states that congenital heart disease is the leading cause of infant deaths due to birth defects; and

Whereas, many newborn lives could be saved by earlier detection and treatment of congenital heart disease if birthing facilities in this State were required to perform screening for the presence of critical congenital heart disease by means of the most appropriate technology; and

Whereas, each day that goes by without appropriate screening places infants at risk; and

Whereas, in the judgment of the Legislature, these facts create an emergency within the meaning of the Constitution of Maine and require the following legislation as immediately necessary for the preservation of the public peace, health and safety; now, therefore,

Be it enacted by the People of the State of Maine as follows:

COMMITTEE AMENDMENT

1 **Sec. 1. 22 MRSA §1532**, as amended by PL 2009, c. 514, §2, is repealed and the
2 following enacted in its place:

3 **§1532. Detection of serious conditions**

4 The department shall require hospitals, birthing centers and other birthing services to
5 test newborn infants, or to cause them to be tested, by means of blood spot screening for
6 the presence of treatable congenital, genetic or metabolic conditions that may be expected
7 to result in subsequent cognitive disabilities, serious illness or death and by means of
8 appropriate technology for the presence of critical congenital heart disease.

9 **1. Define requirement and methods; assistance.** The department shall define the
10 requirement under this section that a newborn infant must be tested for the presence of
11 treatable congenital, genetic or metabolic conditions that may be expected to result in
12 subsequent cognitive disabilities and the approved testing methods, materials, procedures
13 and sequences. Reports and records of those making these tests may be required to be
14 submitted to the department in accordance with departmental rules. The department may,
15 on request, offer consultation, training and evaluation services to those testing facilities.

16 **2. Referrals.** The department shall in a timely fashion refer newborn infants with
17 confirmed treatable congenital, genetic or metabolic conditions or critical congenital
18 heart disease to the Child Development Services System as defined in Title 20-A, section
19 7001, subsection 1-A. The department shall in a timely fashion refer a newborn infant to
20 the Child Development Services System if at least 6 months have passed since an initial
21 positive test result of a treatable congenital, genetic or metabolic condition without the
22 specific nature of the condition having been confirmed. The department and the
23 Department of Education shall execute an interagency agreement to facilitate all referrals
24 made pursuant to this section. In accordance with the interagency agreement, the
25 Department of Education shall offer a single point of contact for the Department of
26 Health and Human Services to use in making referrals. Also in accordance with the
27 interagency agreement, the Child Development Services System may make direct contact
28 with the families who are referred. The referrals may be made electronically. For
29 purposes of quality assurance and improvement, the Child Development Services System
30 shall supply aggregate data to the department at least annually on the numbers of children
31 referred to the Child Development Services System under this section who were found
32 eligible and ineligible for early intervention services. The department shall supply data at
33 least annually to the Child Development Services System on how many children in the
34 newborn blood spot screening program as established by rule of the department under
35 section 1533, subsection 2, paragraph G were screened and how many were found to have
36 a disorder.

37 **3. Religious objection exemption.** The requirement under this section that a
38 newborn infant must be tested for the presence of treatable congenital, genetic or
39 metabolic conditions that may be expected to result in subsequent cognitive disabilities or
40 for the presence of critical congenital heart disease does not apply to a child if the parents
41 of that child object on the grounds that the test conflicts with their religious tenets and
42 practices.

43 **4. Report.** A hospital, birthing center or other birthing service that tests a newborn
44 infant pursuant to this section shall report to the department aggregate data on the testing.

1 including but not limited to the number of infants born, the number tested for treatable
2 congenital, genetic or metabolic conditions, the number screened for critical congenital
3 heart disease, the results of the screening and testing and, for heart disease screening the
4 type of screening tool used.

5 **Sec. 2. Review and report.** The Department of Health and Human Services shall
6 review options for making available to infants born other than in hospitals and birthing
7 centers and through the assistance of other birthing services screening for critical
8 congenital heart disease. The department shall report the results of the review to the Joint
9 Standing Committee on Health and Human Services by April 1, 2014. The department
10 shall perform its duties under this section and under the Maine Revised Statutes, Title 22,
11 section 1532 within existing resources.

12 **Emergency clause.** In view of the emergency cited in the preamble, this
13 legislation takes effect when approved.'

14 SUMMARY

15 This amendment is the majority report of the committee.

16 This amendment changes the title and the emergency preamble and replaces the bill.
17 This amendment adds screening for critical congenital heart disease to the mandatory
18 newborn infant screening law. This amendment requires the entity responsible for the
19 screening to report to the Department of Health and Human Services information on the
20 testing, including but not limited to the number of infants born, the number screened, the
21 type of screening tool used and the results of the screening. The amendment requires the
22 Department of Health and Human Services to review, and report to the Joint Standing
23 Committee on Health and Human Services by April 1, 2014 on, options for making
24 available to infants born other than in hospitals, birthing centers and other birthing
25 services screening for critical congenital heart disease.