

# MAINE STATE LEGISLATURE

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Date: 6/14/13

Majority

L.D. 460  
(Filing No. H-515)

**HEALTH AND HUMAN SERVICES**

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

COMMITTEE AMENDMENT "A" 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1           **Sec. 1. 22 MRSA §1532**, as amended by PL 2009, c. 514, §2, is repealed and the  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.

**FISCAL NOTE REQUIRED**  
**(See attached)**



# 126th MAINE LEGISLATURE

LD 460

LR 757(02)

**An Act To Protect Newborn Infants by Requiring Birthing Facilities To Screen for Congenital Heart Disease Using Pulse Oximetry**

**Fiscal Note for Bill as Amended by Committee Amendment**

**Committee: Health and Human Services**

**Fiscal Note Required: Yes**

*A(CH-515)*

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## Fiscal Note

Current biennium cost increase - Other Special Revenue Funds

### Fiscal Detail and Notes

The bill requires the Department of Health and Human Services to perform the duties required within existing resources. The impact on existing programs and resources cannot be determined.