

STATE OF MAINE

—  
IN THE YEAR OF OUR LORD  
TWO THOUSAND AND THIRTEEN

—  
H.P. 310 - L.D. 460

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

**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:**

**Sec. 1. 22 MRSA §1532**, as amended by PL 2009, c. 514, §2, is repealed and the following enacted in its place:

**§1532. Detection of serious conditions**

The department shall require hospitals, birthing centers and other birthing services to test newborn infants, or to cause them to be tested, by means of blood spot screening for

the presence of treatable congenital, genetic or metabolic conditions that may be expected to result in subsequent cognitive disabilities, serious illness or death and by means of appropriate technology for the presence of critical congenital heart disease.

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

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

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

**4. Report.** A hospital, birthing center or other birthing service that tests a newborn infant pursuant to this section shall report to the department aggregate data on the testing, including but not limited to the number of infants born, the number tested for treatable congenital, genetic or metabolic conditions, the number screened for critical congenital heart disease, the results of the screening and testing and, for heart disease screening the type of screening tool used.

**Sec. 2. Existing resources.** The Department of Health and Human Services shall perform its duties under the Maine Revised Statutes, Title 22, section 1532 within existing resources.

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