

LEGISLATURE OF NEBRASKA  
ONE HUNDRED THIRD LEGISLATURE  
FIRST SESSION  
**LEGISLATIVE BILL 225**

Introduced by Smith, 14.

Read first time January 15, 2013

Committee: Health and Human Services

A BILL

- 1 FOR AN ACT relating to public health and welfare; to adopt the
- 2                   Newborn Critical Congenital Heart Disease Screening Act.
- 3 Be it enacted by the people of the State of Nebraska,

1           Section 1. Sections 1 to 5 of this act shall be known and  
2 cited as the Newborn Critical Congenital Heart Disease Screening Act.

3           Sec. 2. (1) The Legislature finds that:

4           (a) Critical congenital heart disease is among the most  
5 common birth defects;

6           (b) Critical congenital heart disease is the leading  
7 cause of death for infants born with a birth defect;

8           (c) A major cause of infant mortality as a result of  
9 critical congenital heart disease is that a significant number of  
10 newborns affected are not diagnosed in the newborn nursery as having  
11 critical congenital heart disease; and

12           (d) An effective mechanism for critical congenital heart  
13 disease screening of newborns can reduce infant mortality.

14           Sec. 3. For purposes of the Newborn Critical Congenital  
15 Heart Disease Screening Act:

16           (1) Critical congenital heart disease screening means a  
17 testing procedure or procedures intended to detect hypoplastic left  
18 heart syndrome, pulmonary atresia, tetralogy of Fallot, total  
19 anomalous pulmonary venous return, transposition of the great  
20 arteries, tricuspid atresia, and truncus arteriosus;

21           (2) Department means the Department of Health and Human  
22 Services;

23           (3) Birthing facility shall mean a hospital or other  
24 health care facility in this state which provides birthing and  
25 newborn care services;

1           (4) Newborn means a child from birth through twenty-nine  
2 days old; and

3           (5) Parent means a natural parent, stepparent, adoptive  
4 parent, legal guardian, or other legal custodian of a child.

5           Sec. 4. (1) All newborns in this state shall undergo for  
6 critical congenital heart disease screening in accordance with  
7 standards determined in rules and regulations adopted and promulgated  
8 by the department.

9           (2) All birthing facilities in this state shall conduct  
10 critical congenital heart disease screening on newborns and report  
11 the results to the newborn's physician, except that:

12           (a) For deliveries that are planned outside of a birthing  
13 facility, the prenatal care provider shall inform the parent of the  
14 importance of critical congenital heart disease screening and the  
15 requirement for all newborns to be screened; and

16           (b) For a birth that does not take place in a birthing  
17 facility, whether or not there is a prenatal care provider, and the  
18 newborn is not admitted to a birthing facility, the person  
19 registering such birth shall be responsible for obtaining critical  
20 congenital heart disease screening for the newborn.

21           Sec. 5. The department shall:

22           (1) In consultation with a panel of persons having  
23 expertise in the field of critical congenital heart disease  
24 screening, develop approved methods of critical congenital heart  
25 disease screening and protocols for reporting the results;

1           (2) In consultation with a panel of persons having  
2 expertise in the field of critical congenital heart disease  
3 screening, develop a mechanism for hospitals to report data to the  
4 department for the sole purpose of monitoring the effectiveness of  
5 the screening mechanism established under the Newborn Critical  
6 Congenital Heart Disease Screening Act. The department shall annually  
7 report its findings to the Legislature;

8           (3) Develop educational materials explaining critical  
9 congenital heart disease screening and the requirement for all  
10 newborns to be screened. The materials shall be provided to birthing  
11 facilities and health care providers and to parents of newborns not  
12 born in a birthing facility and for which there is no record of the  
13 required screening;

14           (4) Apply for all available federal funding to carry out  
15 the act; and

16           (5) Adopt and promulgate rules and regulations necessary  
17 to implement the act.