GENERAL ASSEMBLY OF NORTH CAROLINA SESSION 2013

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HOUSE BILL 105

Short Title:	Require Pulse Oximetry Newborn Screening.	(Public)
Sponsors:	Representatives Fulghum, Hollo, Stam, and Horn (Primary Sponsors). For a complete list of Sponsors, refer to the North Carolina General Assembly Web	b Site.
Referred to:	Health and Human Services.	

February 14, 2013

A BILL TO BE ENTITLED

2	AN ACT TO EXPAND THE NEWBORN SCREENING PROGRAM ESTABLISHED BY
3	THE DEPARTMENT OF HEALTH AND HUMAN SERVICES TO INCLUDE
4	NEWBORN SCREENING FOR CONGENITAL HEART DISEASE UTILIZING PULSE
5	OXIMETRY, AS RECOMMENDED BY THE NORTH CAROLINA CHILD FATALITY
6	TASK FORCE.
7	Whereas, in 2010, approximately 122,300 babies were born to North Carolina

8 residents; and

9 Whereas, congenital heart defects account for 24% of infant deaths due to birth 10 defects: and

Whereas, more than 1,400 babies with congenital heart defects do not live to 11 celebrate their first birthday; and 12

13 Whereas, in the United States, approximately 4,800 babies born every year have one of seven critical congenital heart defects (CCHDs); and 14

Whereas, infants with one of these CCHDs are at significant risk for death or 15 16 disability if not diagnosed and treated soon after birth; and

Whereas, newborn screening using pulse oximetry, which is a noninvasive test to 17 determine the amount of oxygen in the blood and the pulse rate, can identify some CCHDs 18 19 before infants even show signs of the condition: and

20 Whereas, once identified, infants with CCHDs can receive specialized care and 21 treatment by a cardiologist that could prevent death or disability early in life; and

Whereas, in September 2011, the Secretary of the United States Department of 22 Health and Human Services approved adding screening for CCHDs to the Recommended 23 Uniform Screening Panel upon the recommendation of the Secretary's Advisory Committee on 24 Heritable Disorders in Newborns and Children; Now, therefore, 25

26 The General Assembly of North Carolina enacts: 27

SECTION 1. G.S. 130A-125 reads as rewritten:

"§ 130A-125. Screening of newborns for metabolic and other hereditary and congenital 28 29 disorders.

- 30 (a) The Department shall establish and administer a Newborn Screening Program. The program shall include, but shall not be limited to: 31
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- Development and distribution of educational materials regarding the availability and benefits of newborn screening.
- (2)Provision of laboratory testing.

(1)



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		(3)	Development of follow-up protocols to assure early treatment for identified		
			children, and the provision of genetic counseling and support services for the		
			families of identified children.		
		(4)	Provision of necessary dietary treatment products or medications for		
			identified children as medically indicated and when not otherwise available.		
		(5)	For each newborn, provision of physiological screening in each ear for the		
			presence of permanent hearing loss.		
		<u>(6)</u>	For each newborn, provision of pulse oximetry screening to detect		
			congenital heart defects.		
	(b)		Commission shall adopt rules necessary to implement the Newborn Screening		
	0		les shall include, but shall not be limited to, the conditions for which screening		
shall be required, provided that screening shall not be required when the parents or the guardian					
			ect to such screening. If the parents or guardian object to the screening, the		
			be presented in writing to the physician or other person responsible for		
8	administe		e test, who shall place the written objection in the infant's medical record.		
	(b1)		Commission for Public Health-shall adopt temporary and permanent rules to		
			hearing screening and pulse oximetry screening in the Newborn Screening		
ł	U		hed under this section.		
	<u>(b2)</u>		Commission's rules for pulse oximetry screening shall address at least all of the		
<u>f</u>	following				
		<u>(1)</u>	Follow-up protocols to ensure early treatment for newborn infants diagnosed		
			with a congenital heart defect, including by means of telemedicine. As used		
			in this subsection, "telemedicine" is the use of two-way, real-time interactive		
			audio and video between places of lesser and greater medical capability or		
			expertise to provide and support health care when distance separates		
			participants who are in different geographical locations.		
		<u>(2)</u>	A system for tracking both the process and outcomes of newborn screening		
			utilizing pulse oximetry, with linkage to the Birth Defects Monitoring		
			Program established pursuant to G.S. 130A-131.16.		
_	(c)		of nineteen dollars (\$19.00) applies to a laboratory test performed by the State		
			Public Health pursuant to this section. The fee for a laboratory test is a		
	departmental receipt of the Department and shall be used to offset the cost of the Newborn				
S	Screening				
		SEC	FION 2. This act is effective when it becomes law.		

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SECTION 2. This act is effective when it becomes law.