



HOUSE BILL 698: Baby Carlie Nugent Bill

2015-2016 General Assembly

Committee:		Date:	May 27, 2015
Introduced by:	Reps. Jeter, Lambeth, Adcock	Prepared by:	Theresa Matula
Analysis of:	Second Edition		Committee Staff

SUMMARY: *House Bill 698 requires the Commission for Public Health to adopt rules to implement a screening test for severe combined immunodeficiency (SCID) and other T-Cell lymphopenias detectable as a result of SCID; it authorizes a fee increase from \$19 to \$24; and it contains an appropriation of \$466,132 for the 2015-16 fiscal year to purchase laboratory instrumentation and upgrades to the NC State Laboratory of Public Health.*

CURRENT LAW: G.S. 130A-125 pertains to the screening of newborns for metabolic and other hereditary and congenital disorders. G.S. 130A-25(a) requires the Department to establish and administer a Newborn Screening Program to include the development and distribution of educational materials regarding the availability and benefits of newborn screening; laboratory testing; the development of follow-up protocols to assure early treatment for identified children, and the provision of genetic counseling and support services; the provision of necessary dietary treatment products or medications for identified children; the provision of physiological screening in each ear for the presence of permanent hearing loss; and the provision of pulse oximetry screening to detect congenital heart defects. G.S. 130A-125(c) authorizes a fee \$19.00 for the laboratory test performed by the State Laboratory of Public Health under this section. The fee for a laboratory test is a departmental receipt and must be used to offset the cost of the Newborn Screening Program.

BILL ANALYSIS: **Section 1** of House Bill 698 amends G.S. 130A-125(c) to authorize a fee increase from \$19 to \$24 for the Newborn Screening Program laboratory tests. **Section 2** requires the Commission for Public Health to amend the rules for the Newborn Screening Program to require a screening test for severe combined immunodeficiency (SCID) and other T-Cell lymphopenias detectable as a result of SCID. **Section 3** contains a \$466,132 appropriation to the Department of Health and Human Services, Division of Public Health, for the 2015-16 fiscal year to be used to purchase laboratory instrumentation and upgrades to the existing NC State Laboratory of Public Health Laboratory Information System in order to provide the required informatics capabilities for newborn screening and other laboratory operations.

EFFECTIVE DATE: The bill would become effective July 1, 2015.

BACKGROUND: HB 97, v.5, provides funding for "Pending Legislation" under "Reserves and Debt Service" and HB 698 is listed as pending legislation under item #12 in Section L: Reserves Debt Service and Adjustments, House money report.

Newborns are tested through the State Laboratory of Public Health for a number of conditions and disorders. The following link provides NC newborn screening information: <http://slph.ncpublichealth.com/newborn/default.asp>. The following links are to additional information on SCID: JAMA article on Newborn Screening: <http://jama.jamanetwork.com/article.aspx?articleid=1896983>, Centers for Disease Control and Prevention: <http://www.cdc.gov/newbornscreening/scid.html>.

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