

**GENERAL ASSEMBLY OF NORTH CAROLINA
SESSION 2015**

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**HOUSE BILL 698
Committee Substitute Favorable 5/27/15**

Short Title: Baby Carlie Nugent Bill.

(Public)

Sponsors:

Referred to:

April 15, 2015

A BILL TO BE ENTITLED

1 AN ACT INCREASING THE FEE FOR LABORATORY TESTS PERFORMED BY THE
2 STATE LABORATORY OF PUBLIC HEALTH UNDER THE NEWBORN SCREENING
3 PROGRAM; ADDING A SCREENING TEST FOR SEVERE COMBINED
4 IMMUNODEFICIENCY TO THE NEWBORN SCREENING PANEL; AND
5 APPROPRIATING FUNDS TO THE DEPARTMENT OF HEALTH AND HUMAN
6 SERVICES, DIVISION OF PUBLIC HEALTH, TO PURCHASE NECESSARY
7 EQUIPMENT AND UPGRADES AT THE STATE LABORATORY OF PUBLIC
8 HEALTH FOR NEWBORN SCREENING AND ALL OTHER LABORATORY
9 OPERATIONS.
10

11 Whereas, severe combined immunodeficiency (SCID), often known as "bubble boy
12 disease," is a primary immune deficiency caused by several different genetic defects, most of
13 which are hereditary; and

14 Whereas, children born with SCID lack immunity against bacteria, viruses, and
15 fungi and are prone to repeated and persistent infections that would not cause serious illness in
16 a person or infant with a normal immune system; and

17 Whereas, unless treated early, a child will mostly likely die from opportunistic
18 infections as an infant; and

19 Whereas, it has been known for the past 15 years that early recognition of SCID
20 through newborn screening is critical to successful management of patients with SCID; and

21 Whereas, Baby Carlie Nugent of Harrisburg died in 2000 at the age of 7 months
22 from complications of SCID following a bone marrow transplant because her condition was not
23 diagnosed until she was more than 6 months old; and

24 Whereas, early screening for SCID prior to 3.5 months of age could have saved her
25 life; and

26 Whereas, development and implementation of a screening test for T-Cell
27 lymphopenia has been accomplished, which led to the unanimous recommendation by the
28 United States Secretary of Health and Human Service's Advisory Committee on Heritable
29 Disorders of Newborns and Children in January 2010 to add SCID to the list of conditions
30 routinely screened for at birth; and

31 Whereas, as of November 2014, there are 26 states screening for SCID, and the
32 North Carolina Newborn Screening Advisory Committee unanimously approved adding SCID
33 to this State's newborn screening panel in January 2011, yet SCID screening still has not started
34 in this State; and

35 Whereas, the leading center for treatment of SCID in the United States is located in
36 North Carolina at the Duke University Medical Center; and



1 Whereas, that Center demonstrated in 1999 that, if a bone marrow transplant could
2 be performed before a baby is 3.5 months of age, there is a 94% survival rate, compared with a
3 70% survival rate if the infant is transplanted after that age; and

4 Whereas, infants who do not receive a bone marrow transplant are likely to die
5 before the age of two; and

6 Whereas, in addition to saving lives, the early diagnosis of SCID also saves money,
7 considering the cost of testing a SCID newborn who is not diagnosed until there is a serious
8 infection can range from five hundred thousand dollars (\$500,000) to well over four million
9 five hundred thousand dollars (\$4,500,000), while the cost of transplanting a SCID infant who
10 is not sick is usually less than one hundred thousand dollars (\$100,000); Now, therefore,

11 The General Assembly of North Carolina enacts:

12 **SECTION 1.** G.S. 130A-125(c) reads as rewritten:

13 "(c) A fee of ~~nineteen-twenty-four~~ dollars (~~\$19.00~~)(\$24.00) applies to a laboratory test
14 performed by the State Laboratory of Public Health pursuant to this section. The fee for a
15 laboratory test is a departmental receipt of the Department and shall be used to offset the cost
16 of the Newborn Screening Program."

17 **SECTION 2.** The Commission for Public Health shall amend rules adopted
18 pursuant to G.S. 130A-125 to implement the Newborn Screening Program established under
19 said section to add to the newborn screening panel a screening test for severe combined
20 immunodeficiency (SCID) and other T-Cell lymphopenias detectable as a result of SCID.

21 **SECTION 3.** There is appropriated from the General Fund to the Department of
22 Health and Human Services, Division of Public Health, the sum of four hundred sixty-six
23 thousand one hundred thirty-two dollars (\$466,132) for the 2015-2016 fiscal year. These funds
24 shall be used to purchase laboratory instrumentation and upgrades to the existing North
25 Carolina State Laboratory of Public Health (NCSLPH) Laboratory Information System in order
26 to provide the required informatics capabilities for newborn screening and all other laboratory
27 operations at the NCSLPH.

28 **SECTION 4.** This act becomes effective July 1, 2015.