GENERAL ASSEMBLY OF NORTH CAROLINA
SESSION 2015

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HOUSE BILL 698
Committee Substitute Favorable 5/27/15
PROPOSED SENATE COMMITTEE SUBSTITUTE H698-PCS40517-SH-61

Short Title: Baby Carlie Nugent Bill. (Public)

Sponsors:

Referred to:

April 15, 2015

A BILL TO BE ENTITLED

AN ACT DIRECTING THE COMMISSION FOR PUBLIC HEALTH TO ADOPT RULES TO ADD A SCREENING TEST FOR SEVERE COMBINED IMMUNODEFICIENCY AND OTHER T-CELL LYMPHOPENIAS TO THE NEWBORN SCREENING PROGRAM.

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

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

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

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

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

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

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

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

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

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

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

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

The General Assembly of North Carolina enacts:

SECTION 1. The Commission for Public Health shall amend rules adopted pursuant to G.S. 130A-125 to implement the Newborn Screening Program established under said section to add to the newborn screening panel a screening test for severe combined immunodeficiency (SCID) and other T-Cell lymphopenias detectable as a result of SCID.

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