

## **SUPPORT HB 698 (Baby Carlie Nugent Bill) to Add Severe Combined Immunodeficiency to Newborn Screening Panel to Save Lives and Health Care Costs June 2015**

**Severe Combined Immunodeficiency (SCID) is treatable when caught early:** SCID, also known as the “bubble boy” disease, can be treated with a bone marrow transplant. Treatment during the first 3.5 months of life greatly increases the chance of survival (93% compared to 69%). Indeed, the efficacy of treatment is much higher for SCID than for most of the metabolic diseases for which we screen. Untreated, the condition is fatal before the first birthday.

**Screening for SCID is best practice:** The screen is recommended by the Secretary’s Advisory Committee on Heritable Disorders of Infants and Children, the US Secretary of HHS, and the NC Newborn Screening Committee. Most other states (29) screen for SCID.

**The incidence of SCID is higher than initially thought:** Earlier estimates were that about 1 out of every 100,000 newborns had SCID. However, as more states have begun screening, a recent analysis published in the Journal of the American Medical Association found the incidence to be 1:58,000. (Experts suggest that many infant deaths were previously attributed to pneumonia or other infections before a diagnosis of SCID was established) North Carolina has approximately 120,000 to 130,000 births each year.

**North Carolina has a low newborn screening fee:** At \$19, NC’s fee is the 6<sup>th</sup> lowest in the nation. Our surrounding states also have fees at least twice as much: SC \$68.51; TN \$75; and VA \$53.

**The cost of treating SCID when babies are healthy is about 1/20 the cost of performing a transplant for sicker SCID babies due to the cost of treating their infections.** Diagnosing SCID at birth allows the transplant to be performed before infections have been acquired due to the infant’s absent immune system. In the 5-20-15 House Health Committee hearing, Dr. Becky Buckley, Professor of Pediatrics and Immunology at Duke University Medical Center, which has done more SCID transplants than any other single center in the world and has one of the highest survival rates, testified the cost of treatment is about \$100,000 for a healthy SCID infant. In contrast, the four North Carolina babies she has transplanted over the past 5 years, all of whom were diagnosed late and were very sick incurred costs totaling \$14 million. (Of that sum, \$10 million was charged to Medicaid and \$4 million to private insurance.)

**H698 Details:** The Baby Carlie Nugent Bill adds SCID to the required panel of newborn screening. It uses \$466,000 in funding from the House Budget (H97) to match a federal grant (HRSA) for a one-time purchase of equipment and related programming and training. It increases the newborn screening fee from \$19 to \$24 to cover the marginal cost of the screen. It passed the House 109-1.