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# Memo

**To:** Birthing Hospitals, Birthing Centers, Physician Offices, and Health Departments

**From:** Scott J Zimmerman, DrPH, MPH, HCLD (ABB)   
Director, NC State Laboratory of Public Health

**Date:** April 17<sup>th</sup>, 2017

**Re:** Newborn Screening Pilot for Severe Combined Immunodeficiency (SCID)

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The North Carolina State Laboratory of Public Health (NCSLPH) in collaboration with RTI International is conducting a pilot study to screen for severe combined immunodeficiency (SCID) also known as “bubble boy disease” as well as other causes of severe T cell lymphopenia. SCID is a group of disorders characterized by profound impairment of T-cell development and function. Babies with SCID will appear healthy at birth but will quickly become vulnerable to persistent reoccurring infections. Hematopoietic stem cell transplantation (HSCT) is the recommended treatment for this disorder to reconstitute the immune system and has a high success rate when performed within the first few months of life.

The Advisory Committee on Heritable Disorders in Newborns and Children and the U.S. Secretary of Health and Human Services recommended and approved this condition for inclusion in the Recommended Uniform Screening Panel (RUSP) in 2010. SCID screening has been successfully implemented in 43 states. In 2015, North Carolina signed into law the Baby Carlie Nugent Bill/House Bill 698 allowing the North Carolina State Laboratory of Public Health (NCSLPH) to implement screening for SCID.

NCSLPH will first conduct a pilot study to optimize testing conditions for identifying babies at risk for SCID or other causes of severe T cell lymphopenia and then will integrate the screening program into the standard newborn screening panel. The pilot study will be statewide and will use the dried blood spot specimens collected and submitted to the NCSLPH from the initial newborn heel stick specimen. For the majority of cases, no additional specimen will be required for SCID risk assessment. However, health care providers will be contacted if an additional specimen is needed for further evaluation or if pilot study results identify an elevated risk for SCID or other T-cell lymphopenias. **Results obtained during the pilot study will not appear on the newborn screening report.** Results obtained from babies that suggest an elevated risk for SCID will be communicated to the health care provider by phone call and fax. Follow-up personnel will provide consultation services and recommendations for follow-up testing and precautionary measures to avoid exposure to infections. Testing is scheduled to begin on **April 24<sup>th</sup>, 2017** and will continue until fully integrated into the standard newborn screening panel.

Please contact Dr. Jennifer Taylor at (919) 733-3937 or see the Immune Deficiency Foundation (<http://primaryimmune.org/about-primary-immunodeficiencies/specific-disease-types/severe-combined-immune-deficiency-and-combined-immune-deficiency/>) for more information.

Thank you for your attention to this important announcement.