



DEPARTMENT OF HEALTH AND HUMAN SERVICES
DIVISION OF PUBLIC HEALTH, STATE LABORATORY OF PUBLIC HEALTH

ROY COOPER
GOVERNOR


MANDY COHEN, MD, MPH
SECRETARY

DANIEL STALEY
DIRECTOR

SCOTT J. ZIMMERMAN, DRPH, MPH, HCLD (ABB)
LABORATORY DIRECTOR

Memo

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

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

Date: November 17, 2017

Re: Newborn Screening for Severe Combined Immunodeficiency (SCID) pilot study ending with full integration of SCID into standard newborn screening panel.

The North Carolina State Laboratory of Public Health (NCSLPH) in collaboration with RTI International has concluded a successful pilot study to screen for severe combined immunodeficiency (SCID) also known as "bubble boy disease" that began April 24th, 2017. The screening for babies at risk for SCID or other causes of severe T-cell lymphopenia will now be integrated into the standard newborn screening panel and the results will be included on the NCSLPH Newborn Screening Report; reports are issued in hardcopy form and are also available via the online results portal. Implementation of SCID screening in North Carolina (NC) is possible due to the NC General Assembly's "Baby Carlie Nugent Bill" which authorize NCSLPH to implement screening for SCID.

<http://slph.ncpublichealth.com>
Tel 919-733-7834 • Fax 919-733-8695
Location: 4312 District Drive • Raleigh, NC 27607
Mailing Address: 1918 Mail Service Center • Raleigh, NC 27699-8057
P.O. Box 28047 • Raleigh, NC 27611-8047
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Laboratory screening results that suggest an elevated risk for SCID will be initially communicated to the health care provider by phone or fax and a hardcopy report will follow. The NC Follow-up Program will provide consultation services and recommendations for follow-up testing and precautionary measures to avoid exposure to infections. A pre-recorded webinar explaining more in depth what SCID is and how it will be reported on the newborn screening report can be accessed at <http://slph.adobeconnect.com/pbje20z5v87s/>. **Newborn screening reports going out on or after December 4, 2017 will have SCID results included on the report.** Any specimens reported before then will still be reported per the pilot program protocol.

Please contact Henry Persons at (919) 807-8775 or see the Immune Deficiency Foundation website (<https://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.