



Date: July 21, 2015

From: State Hygienic Laboratory at the University of Iowa (SHL)
South Dakota Newborn Screening Program (SDNSP)

RE: NEWBORN SCREENING IMPLEMENTATION DATE CHANGE
Screening for Severe Combined Immunodeficiency (SCID) will begin September 1, 2015.

The South Dakota Newborn Screening Program has completed the required administrative rule process to begin statewide newborn screening for Severe Combined Immune Deficiency (SCID) effective **September 1, 2015**. The testing will be done through the SDNSP contract designated laboratory, the State Hygienic Laboratory at the University of Iowa (SHL).

What is SCID?

SCID is a rare inherited disorder caused by a deficiency or absence of T cells. The symptoms of SCID include recurrent life-threatening infections, failure to thrive, diarrhea, and thrush. The average age of diagnosis is approximately 6 months. If not treated, most patients do not survive past one year of age. The incidence of SCID is estimated to be 1 in 50,000 to 1 in 60,000. There are more than 15 known genetic causes of SCID. Early detection of this disorder allows for infants to receive necessary life-saving treatment including antibiotics, isolation precautions, and a bone marrow or stem cell transplant, if needed.

Screening for SCID involves T-cell receptor excision circle (TREC) analysis. Although the TREC assay is designed to detect SCID, in some instances it can also detect other T-cell disorders such as 22q deletion syndromes (i.e. DiGeorge anomaly) and certain congenital malformations associated with lymphopenia.

Over recent weeks, newborn screening providers across South Dakota have received information from the SDNSP about the addition of SCID to the newborn screening panel. To ensure hospital laboratory systems and business procedures have had adequate time to make necessary changes to their operations, the implementation date has been extended 3 weeks to **September 1, 2015**.

- The newborn screening fee will increase from the current rate of \$65.00 to \$75.00 on **September 1, 2015**.
- There will be no charge for repeat specimens when requested by the SHL or the SDNSP.
- Sample laboratory reports of possible SCID test results are included.
- **Specimen collection will not change from current procedures - nothing different needs to be done.**
- Additional SCID information is available upon request. If interested, please contact the South Dakota Newborn Screening Program at 1-605-773-3361. SCID information is also available to download from the SDNSP website:

<http://doh.sd.gov/family/newborn/metabolic/SCID/>

Questions regarding SCID screening may be directed to the following person:

Questions for the South Dakota Newborn Screening Program:

Lucy Fossen, South Dakota Newborn Screening Program Coordinator
605-773-3361 or 1-800-738-2301
lucy.fossen@state.sd.us

SHL Newborn Screening Laboratory Questions:

Stan Berberich, Ph.D.
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Screening Follow-up and Treatment Questions:

Sarah Groeneveld, RN
South Dakota Newborn Screening Program, Follow-up Coordinator

Archana Chatterjee, MD
SDNSP Medical Consultant for SCID
605-773-3361

The SHL and SDSNP intend to work closely with you to implement screening for SCID with the goal of saving the lives and improving outcomes for affected infants. We apologize for any confusion the change in implementation date may have caused. Please feel free to contact us with any questions regarding this change.

Sincerely,

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