



Support Screening for Severe Combined Immunodeficiency (SCID) as part of a state's newborn screening panel.

Screening newborns for SCID saves lives.

What is SCID?

Severe Combined Immunodeficiency (SCID) is a term that describes a group of rare inherited disorders characterized by defects in two critical immune system cells that are normally mobilized by the body to combat infections. SCID has been referred to in the popular media as the "bubble boy disease." SCID is not very common and experts estimate approximately 40-100 infants are diagnosed with SCID in the United States every year. The Secretary of the U.S. Department of Health and Human Services added screening for SCID to the Recommended Uniform Screening Panel (RUSP) in May 2010.

Why Screen for SCID?

Without treatment, infants with SCID are more susceptible to and can develop recurrent infections, leading to failure to thrive and oftentimes death. Treatments are available to significantly enhance the health outcomes of infants with SCID who are pre-symptomatic or early symptomatic. Based on several large studies, hematopoietic stem cell transplant from either umbilical cord blood or bone marrow appears to be effective in significantly decreasing the morbidity and mortality associated with SCID.

Screening for SCID

SCID can be identified using dried blood spots, but laboratories will need to use a new test not related to any of the others currently used for newborn screening. This screening test measures a deficiency in counts of genetic material known as T-cell receptor excision circles (TREC). Based on preliminary data from its newborn screening program, Wisconsin has estimated the cost of the screening to be about \$6 per sample, in addition to laboratory start-up costs.

Newborns should be Screened for SCID

March of Dimes supports newborn screening for conditions and disorders for which there is a documented medical benefit to the affected infant from early detection and treatment; there is a reliable screening test for the disorder; and early detection can be made from newborn blood spots or other specific means.

Early detection for SCID via newborn screening will allow affected infants to receive such life-saving interventions promptly. Evidence suggests that the earlier a newborn can receive treatments (e.g., within the first three months of life), the higher the success rate.

Key Points

- SCID, or "bubble boy disease," is a term that describes a group of rare inherited disorders characterized by defects in two critical immune system cells that are normally mobilized by the body to combat infections..
- Without treatment, infants with SCID are more susceptible to and can develop recurrent infections, leading to failure to thrive and oftentimes death.
- Evidence suggests that the earlier a newborn can receive treatments (e.g., within the first three months of life), the higher the success rate.
- SCID can be identified using dried blood spots, but laboratories will need to use a new test not related to any of the others currently used for in newborn screening.
- Screening has been estimated to cost \$6.00 per infant, in addition to laboratory start-up costs.

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