

Newborn Screening for Severe Combined Immune Deficiency (SCID)

What Is Severe Combined Immune Deficiency (SCID)?

- SCID is a fatal disorder in which infants fail to develop a normal immune system.
- If undetected and untreated, SCID typically leads to death before the baby's 1st birthday.
- If a baby with SCID receives a bone marrow transplant in the first 3.5 months of life, the survival rate can be as high as 94%.

SCID: Pediatric Emergency

- SCID has been characterized in the medical community as a pediatric emergency.
- There is no easy way to recognize SCID as babies with SCID appear healthy at birth.
- Many infants are not identified until they develop repeated life-threatening infections.
- SCID is the most serious of the primary immunodeficiency diseases, a group of more than 300 rare, chronic disorders in which part of the body's immune system is missing or functions improperly.

Occurrence of SCID

- 1 out of every 55,000 live births, estimating 72 -100 babies are diagnosed per year in the U.S.
- It is estimated that 2 to 4 of these infants will be born in Arizona.
- SCID is as common as many of the inherited illnesses for which states currently screen all newborns.

Cost and Survival Rate for Early Treatment

- Cost of early treatment (within first 3.5 months) before infections develop can be as low as \$50,000 per infant.

Cost and Survival Rate for Late Treatment

- Over \$2,300,000 for treatment of one Arizona baby born off of reservation in 2015.
- Early infections often lead to lifelong medical complications.
- The survival rate drops to less than 70% for infants who receive a transplant after the first 3.5 months of life.

Cost of Newborn Screening Test

- A newborn screening test (TREC) has been developed and recommended by the U.S. Department of Health and Human Services and the CDC as the preferred way to screen newborns for SCID.
- TREC is currently being implemented in 43 states and has an estimated cost of \$6 per infant screened from the vendor that Arizona Department of Health anticipates using.

Bonus – Additional Conditions Identified by TREC Test

- TREC testing will also identify other conditions in newborns including DeGeorge Syndrome, Trisomy 21, Ataxia Telangiectasia, CHARGE Syndrome, Vascular Leakage, Neonatal Leukemia and other congenital anomalies.

Fiscal Costs/Benefits for Arizona

- Cost for FDA approved test kit: \$6.00 x 90,000 live births = \$540,000.
- Cost to the Arizona Medicaid program, Arizona Health Care Cost Containment System (AHCCCS) = \$167,400.
- Cost per unidentified and untreated newborn with SCID: \$2.5 million.
- At an estimated 2-4 infants born with SCID in Arizona, with at least one of which would be Medicaid covered, the state would recover its cost for test kits and save the state budget \$1.5 million every year by diagnosing early.

Arizona is 1 of only 7 states NOT currently screening for SCID:

Alabama*, Arizona, Indiana, Kansas*, Louisiana, Nevada*, North Carolina*

** States Planning to Implement Screening in 2017*

The sooner a child is diagnosed with SCID, the sooner treatment can begin and more likely it is to be effective.



The National Non-profit Patient Organization Dedicated to Improving the Diagnosis, Treatment and Quality of Life of Persons with Primary Immunodeficiency Diseases through Advocacy, Education and Research

www.primaryimmune.org



SCID, Angels for Life Foundation

www.scidangelsforlife.com