



IMMUNE DEFICIENCY FOUNDATION

The National Patient Organization Dedicated to Advocacy, Education and Research for Primary Immunodeficiency Diseases

Facts about Severe Combined Immunodeficiency Disease and Newborn Screening

- SCID, or severe combined immunodeficiency disease, is a treatable illness in which an infant fails to develop a normal immune system. After successful treatment, people with SCID lead normal lives.
- SCID is a pediatric emergency, and newborn screening offers an opportunity to catch the disease early when treatment is most effective and cost efficient.
- A wide range of viruses, bacteria and fungi that are normally controlled by a healthy baby's immune system can cause serious infections in SCID babies.
- If undetected and untreated, SCID typically leads to death before the baby's first birthday.
- SCID can now be cured with a bone marrow transplant if diagnosed and treated in the first weeks or months of life. One form of the disease can be treated with an injectable medication.
- Newborn screening would provide a rapid indication of a possible immune problem soon after birth while the infant is still protected by the mother's antibodies.
- Research shows that bone marrow transplants in the first three months of life have a higher rate of efficacy than transplants at a later age.
- Early treatment for SCID can also reduce medical costs – the cost of a transplant in the first three months of life can be measured in tens of thousands, but the cost of delayed care can reach into the millions for seriously ill patients with less guarantee of success.
- The poor quality of life in late-diagnosed SCID patients, often caused by complications of infections that started before diagnosis, can eventually lead to disability or even death.

Immune Deficiency Foundation (IDF) applauds the Secretary of Health and Human Service's inclusion of SCID in the new national standards.

IDF asks every state to include SCID Newborn Screening on their newborn screening panel immediately to save lives.