



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

## **Questions about Newborn Screening for Severe Combined Immunodeficiency (SCID)**

### **What is SCID screening in Newborns?**

SCID screening in newborns became possible just a few years ago with the development of a test that can detect SCID in the dried blood spot filter cards that are currently collected from all babies to screen for a variety of inborn conditions. Prominent immunologists contend that this simple blood test could allow doctors to treat, and most likely cure, SCID in an infant at a reasonable cost, as opposed to endless, less-effective diagnostic procedures and treatments that could lead to enormous medical expenses after a child has developed an infection.

### **Has SCID screening in Newborns Been Supported by Public Policy?**

In January 2010, the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) recommended to the Secretary of the Department of Health and Human Services, Kathleen Sebelius, that the Federal government recommend to the States that they include SCID in their newborn screening protocols. The ACHDNC adopted a list of 29 recommended conditions for screening in September 2005. Since that time, SCID is the first condition to be added to this list for inclusion into mandatory newborn screening conducted by state public health programs. On May 21, 2010, Kathleen Sebelius, Secretary of Health and Human Services (HHS) announced her decision to concur with the committee and add SCID to the core panel of disorders for newborn screenings.”

### **What is the ACHDNC?**

The Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), an evidence-based committee, was chartered in February 2003 to advise the Secretary regarding the most appropriate application of universal newborn screening tests, technologies, policies, guidelines and standards for effectively reducing morbidity and mortality in newborns and children having, or at risk for, heritable disorders. The committee unanimously voted to recommend adding SCID to the core newborn screening panel.

### **Do Any States Currently Screen Newborns for SCID?**

In 2007, Wisconsin began a four-year pilot program to evaluate statewide newborn screening for SCID. State officials have tentatively concluded that screening costs are reasonable and that cost-effective treatment is available for newborns diagnosed early in life with SCID. These conclusions have been published in peer-reviewed papers in the December 2009 Journal of the American Medical Association (JAMA) and the April 2009 Journal of Allergy and Clinical Immunology (JACI). Massachusetts also began a SCID newborn screening pilot program in February 2009. In 2010, California, New York, Louisiana, and Puerto Rico began SCID screening programs. In 2011, Michigan and Colorado also began SCID screening programs. Connecticut and Delaware plan to begin statewide screening for SCID before the end of 2011.

### **What kind of test is used to screen for SCID?**

The SCID-screening test currently utilized uses the same dried blood samples already collected from newborns. The TREC test is an assay that detects the number of T-cell Receptor Gene Excision Circles, or TRECs, that are produced during normal T-cell maturation, but that are absent or severely reduced in infants with SCID. The TREC test, which is performed on newborn dried blood samples, is very sensitive and has a false positive rate well below 1%.

*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.*