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Immune Deficiency Foundation Praises Illinois Genetic and Metabolic Diseases Advisory Committee on Vote to Recommend SCID Screening for Newborns

Springfield, IL and Towson, MD – The Illinois Genetic and Metabolic Diseases Advisory Committee voted unanimously to recommend that the Department of Health screen all newborns for Severe Combined Immune Deficiency (SCID) - commonly known as bubble boy disease.

The Immune Deficiency Foundation (IDF), the national patient organization for persons with primary immunodeficiency diseases, commends the state of Illinois for taking this momentous step. IDF continues to support and work tirelessly for universal SCID newborn screening. “It is imperative that we sustain this momentum by establishing newborn screening programs in all 50 states,” said Marcia Boyle, President & Founder of IDF.

SCID is a primary immunodeficiency disease where affected infants lack T lymphocytes or white blood cells that help fight infections from a wide array of viruses, bacteria and fungi. Babies with SCID appear healthy at birth, but without early treatment, most often by bone marrow transplant from a healthy donor, these infants cannot survive. SCID infants who receive treatment within months of birth have a greater possibility of living healthy and productive lives.

The decision by the Advisory Committee follows the recommendation of Health and Human Services Secretary Kathleen Sebelius that SCID be included among the disorders for which all states screen newborns.

Elwood, IL resident Amy Walsh, IDF volunteer and mother to a child with a T lymphocyte deficiency, presented to the Committee about the importance of early detection. Ms. Walsh joined the Illinois Newborn Screening Expansion subcommittee with the hopes of helping to draft a protocol regarding the proposal and approval of additions to the newborn screening test panel.
"I am excited that the advisory committee voted unanimously to recommend SCID Newborn Screening," expressed Ms. Walsh, “I am hopeful that once Illinois begins screening, no more Illinois infants will lose their lives because of a late diagnosis of SCID."

For more information about the IDF SCID Newborn Screening Campaign and other primary immunodeficiency diseases, please contact IDF at 800-296-4433, idf@primaryimmune.org, or visit the IDF website at www.primaryimmune.org.

**About the Immune Deficiency Foundation**
The Immune Deficiency Foundation is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education, and research.