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Immune Deficiency Foundation Praises Florida Genetics and Newborn Screening Program Advisory Council on Vote to Recommend SCID Screening for Newborns

Jacksonville, FL and Towson, MD – The Florida Genetics and Newborn Screening Program Advisory Council 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 Florida 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 Council follows the recommendation of Health and Human Services Secretary Kathleen Sebelius that SCID be included among the disorders for which all states screen newborns.

Heather Smith, co-founder of SCID Angels for Life and IDF volunteer, who lost her seven-month-old son Brandon to this devastating disease, presented to the Council about the importance of early detection using her own tragedy as an example. Ms. Smith joined 12 other
volunteers from the IDF community at the meeting in a show of support for the implementation of SCID newborn screening.

“History was made when the committee voted unanimously to add SCID to their current screening panel, as I was told this had never been done by the committee before,” concluded Ms. Smith, “Babies lives will be saved in Florida!”

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.