



IMMUNE DEFICIENCY FOUNDATION

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

FOR IMMEDIATE RELEASE

Secretary of Health and Human Services Announces Addition of SCID To National Newborn Screening Standards

TOWSON, MD, MAY 25, 2010 – On May 21, 2010, Kathleen Sebelius, Secretary of Health and Human Services (HHS) announced the addition of Severe Combined Immunodeficiency (SCID)—commonly known as bubble boy disease—to the core panel of 29 genetic disorders - as part of her recommendation to adopt the national Recommended Uniform Screening Panel. The Secretary made her announcement in a letter to Dr. Rodney Howell, Chair of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC). SCID is the first nominated condition to be added to the core panel of disorders.

SCID is a primary immunodeficiency disease. Affected infants lack T lymphocytes, the white blood cells that help resist infections due to 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.

The Immune Deficiency Foundation (IDF), the national patient organization for persons with primary immunodeficiency diseases, applauds the action by Secretary Sebelius for including SCID in the new national standards. "The addition of SCID to the national newborn screening standards is a momentous step forward for the primary immunodeficiency community," said Marcia Boyle, President & Founder of IDF. "The IDF has strongly supported and worked tirelessly toward this goal for years. It is imperative that we sustain this momentum by establishing newborn screening programs in all 50 states."

"Although this recommendation has been in development for two years," said Dr. Amy Brower, parent, researcher and former SACHDNC committee member, "it may take several more years to implement screening in all 50 states and US territories. We must work to quickly implement the widespread adoption of testing and treatment in all of the states."

"As the parent of a child who was diagnosed with SCID only after he became critically ill," said Barb Ballard, a member of the IDF Board of Trustees, "I am immensely pleased with the action taken by Secretary Sebelius."

"Our goal is to have Newborn Screening for SCID passed in all 50 states," said Heather Smith, co-founder of SCID Angels for Life, who lost her seven-month-old son, Brandon, to this devastating disease.

For more information, please contact IDF at 800-296-4433, or idf@primaryimmune.org. Or visit the IDF website at www.primaryimmune.org.

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