



American College of Medical Genetics

Medical Genetics: Translating Genes Into Health®

ACMG NEWS

For Immediate Release

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The American College of Medical Genetics Supports the Recommendations to Include SCID in Universal Newborn Screening Panel

Bethesda, MD – February 1, 2010 | Last week, the Secretary's Advisory Committee for Heritable Disorders in Newborns and Children (ACHDNC) unanimously agreed to recommend that Severe Combined Immunodeficiency (SCID), which is more commonly known as "bubble boy disease," be added to the universal newborn screening programs conducted by state public health agencies. "The American College of Medical Genetics (ACMG) wholeheartedly supports the Federal Advisory Committee's recommendation that Severe Combined Immunodeficiency be added to the uniform newborn screening panel developed by ACMG in 2005. It is one of the best new examples of a condition for which early identification and treatment can totally transform the outcome of those who are affected," said Michael S. Watson, PhD, FACMG, executive director of the American College of Medical Genetics, and a liaison to the Secretary's Advisory Committee.

According to the Immune Deficiency Foundation, SCID is a primary immunodeficiency. 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. "With early identification through newborn screening, these infants can be treated and their lives both greatly improved and prolonged," added Dr. Watson.

The ACHDNC recommendation highlighted three areas that need to be addressed to initiate screening; 1) Educational materials for the providers, the public, and those who screen positively; 2) quality assurance materials for the screening laboratories; and 3) diagnosis and follow-up protocols and a network of providers who can deliver these services.

For more information about Universal Newborn Screening visit the American College of Medical Genetics website at www.acmg.net.

About the American College of Medical Genetics and ACMG Foundation

Founded in 1991, the American College of Medical Genetics (www.acmg.net) is the national non-profit professional organization that advances the practice of medical genetics by providing education, resources and a voice for physician geneticists, biochemical, clinical, cytogenetic, medical and molecular geneticists, genetic counselors and other healthcare professionals committed to the practice of medical genetics. ACMG's website (www.acmg.net) offers a variety of resources including Policy Statements, Practice Guidelines, Educational Resources, and a Medical Geneticist Locator. The educational and public health programs of the American College of Medical Genetics are dependent upon grants and contracts and charitable gifts from corporations, foundations, and individuals. The American College of Medical Genetics Foundation (www.acmgfoundation.org) is a 501(c)(3) not-for-profit organization dedicated to funding the College's diverse efforts to translate genes into health.

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