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Federal Advisory Committee Recommends SCID for Universal Newborn Screening

WASHINGTON – January 27, 2010 – In a historic vote on January 21, 2010, the Secretary's Advisory Committee for Heritable Disorders in Newborns and Children (ACHDNC) unanimously agreed to recommend the addition of Severe Combined Immunodeficiency (SCID) to the uniform newborn screening panel. The ACHDNC adopted a list of 29 recommended conditions 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.

SCID is a group of disorders characterized by the absence of an immune system, causing infants with SCID to develop recurrent infections, leading to death in early childhood. SCID affects a minimum of one in 100,000 newborns; however, some studies estimate that the actual number is closer to one in 40,000. Treatment in the first months after birth can prolong life and prevent infections. Wisconsin and Massachusetts both developed cost-effective methods for universal screening for SCID, and a number of other states have started to train their laboratory personnel to start screening for SCID.

Dr. Rebecca Buckley of Duke University Medical Center published the first article showing the effectiveness of early bone marrow transplantation as a treatment for SCID in 1999 in *The New England Journal of Medicine*. After working for 13 years to get SCID added to the recommended panel, the vote came as "a dream come true."

The Chairman of the ACHDNC, Dr. R. Rodney Howell, noted that "[the Advisory Committee] has carefully reviewed the detailed, updated evidence review for SCID and related T-lymphocyte deficiencies and found the condition(s) ready to be added to the uniform and secondary panel. … The Advisory Committee, however, understands that there will be additional work from the NIH, HRSA and the CDC to be reported back to the Committee as this newborn screening proceeds."

The ACHDNC was established in February 2003 to advise the Secretary of the U.S. Department of Health and Human Services 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. There is currently a formal process for individuals or organizations to nominate a heritable disorder to be considered for inclusion in the recommended uniform screening panel (http://www.hrsa.gov/heritabledisorderscommittee/nominate.htm).

"This recommendation by the [Advisory] Committee is significant for both newborn screening and for the evidence-based process for decision making," declared Sharon Terry, president and chief executive officer of Genetic Alliance, who serves as a liaison on the ACHDNC. "The

recommendation includes surveillance, education and quality control, to be contributed by the National Institutes of Health, Health Resources and Services Administration and Centers for Disease Control and Prevention, and thereby supports the development of a systems approach in newborn screening."

To date, six conditions have been brought to the Advisory Committee: Fabry Disease, Krabbe Disease, Niemann-Pick Disease, Pompe Disease, Severe Combined Immunodeficiency (SCID), and Spinal Muscular Atrophy (SMA). Thus far, only SCID has been recommended for addition to the uniform screening panel. By law, the Secretary of Health and Human Services must respond to the recommendation within 180 days.

Vicki Modell, co-founder of the Jeffery Modell Foundation, stated that "[the] unanimous vote to add SCID to the National Newborn Screening Core Panel was a milestone victory. We thank the Committee for their positive decision on behalf of all the babies with SCID that we lost, the babies today who have hope, and for all the future babies yet to be born, who will have a really good chance at life."

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About Genetic Alliance

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