



Association of Maternal and Child Health Programs (AMCHP) Commends Congressional Action on Newborn Screening

Washington, DC, April 8,– Michael Fraser, PhD., Chief Executive Officer of the Association of Maternal and Child Health Programs (AMCHP), issued this statement today in anticipation of a vote on the Newborn Screening Saves Lives Act (S 1858) in the U.S. House of Representatives:

“Every child deserves the healthiest possible start in life. Today, the U.S. Congress is taking an important step to help assure that all states have the resources and tools needed to expand and enhance comprehensive newborn screening programs.”

“These vital public health programs routinely screen all newborns for certain genetic, metabolic, and functional disorders. Most of these conditions have no immediately visible effects on a baby, but can cause physical problems, mental retardation and, in some cases, death - unless detected and treated early.”

The Newborn Screening Saves Lives Act authorizes the resources states need to improve detection and treatment, and to implement recommendations for all states to screen for a minimum of 29 disorders. Treatment is currently available for each of the recommended conditions, which are identified in a report by the American College of Medical Genetics (ACMG) commissioned by the U.S. Health Resources and Services Administration.

This legislation authorizes funding for initiatives that:

- enhance, improve or expand the ability of state and local public health agencies to provide screening, counseling, or health care services to newborns and children having or at risk for heritable disorders;
- assist in providing health care professionals and newborn screening laboratory personnel with education in newborn screening and training in relevant and new technologies in newborn screening;
- develop and deliver education about newborn screening counseling, testing, follow-up, treatment, and specialty services to parents, families, and patient advocacy and support groups; and
- establish, maintain and operate a system to assess and coordinate treatment relating to congenital, genetic and metabolic disorders.

AMCHP commends Congress for acting on this important legislation, and extends special thanks to Rep. Lucille Roybal-Allard (D-CA), Rep. Tom Reynolds (R-NY), Rep. Mike Simpson (R-ID), and Rep Henry Waxman (D-CA), sponsors of the House bill and Sen. Chris Dodd (D-CT), Sen. Hillary Clinton (D-NY) and Sen. Orrin Hatch (R-UT), sponsors of the Senate bill that passed unanimously in Dec. 2007. We urge final passage of this bill to help assure that all children receive a healthy start in life.

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AMCHP is the national organization representing state public health leaders and others working to improve the health and well-being of women, children and youth, including those with special health care needs, and families. For more information, visit www.amchp.org.