The Newborn Screening Saves Lives Reauthorization Act (H.R. 1281/S. 1417)

The Newborn Screening Save Lives Reauthorization Act reauthorizes critical federal programs that provide assistance to states to improve and expand their newborn screening programs; support parent and provider education; and ensure laboratory quality and surveillance for newborn screening.

Background

• In 2008, Congress passed the original Newborn Screening Saves Lives Act (P.L. 110-204), which established national newborn screening guidelines and helped facilitate comprehensive newborn screening in every state.

• Prior to passage of P.L. 110-204, the number and quality of newborn screening tests varied greatly from state to state.

• In 2007, only 10 states and the District of Columbia required infants to be screened for all the recommended disorders. Today, 44 states and the District of Columbia require screening for at least 29 of the 31 treatable core conditions.

Key Bill Provisions

• Reauthorizes the Health Resources and Services Administration (HRSA) grants to states to expand and improve their screening programs, educate parents and health care providers, and improve follow-up care for infants with a condition detected through newborn screening.

• Reauthorizes the Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children, which provides states with a Recommended Uniform Screening Panel to help ensure every infant is screened for conditions which have a known treatment. Also establishes a timeline for review of conditions that have been nominated for the recommended uniform screening panel.

• Reauthorizes HRSA’s Clearinghouse for Newborn Screening Information and the Newborn Screening Technical Assistance and Evaluation Program (NewSTEPs).

• Reauthorizes the Centers for Disease Control and Prevention Newborn Screening Quality Assurance Program, the only comprehensive program devoted to ensuring the accuracy of newborn tests.

• Reauthorizes the National Institutes of Health Hunter Kelly Newborn Screening program, which funds research aimed at identifying new treatments for conditions that can be detected through newborn screening and developing new screening technologies.

Screening Facts

• Newborn screening reaches each of the more than 4 million babies born in the U.S. every year.

• Approximately 1 in every 300 newborns has a condition that can be detected through screening.

• Newborn screening is the practice of testing every newborn for certain genetic, metabolic, hormonal and functional conditions that are not otherwise apparent at birth.

• Screening detects conditions that, if left untreated, can cause disabilities, developmental delays, illnesses or even death. If diagnosed early, many of these disorders can be managed successfully.

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The March of Dimes is a national voluntary health agency whose volunteers and staff work to improve the health of infants and children by preventing birth defects, premature birth and infant mortality. Founded in 1938, the March of Dimes funds programs of research, community services, education and advocacy. For the latest resources and information, visit marchofdimes.org or nacersano.org.