

# **NEWBORN SCREENING SAVES LIVES REAUTHORIZATION ACT OF 2019**

The *Newborn Screening Save Lives Reauthorization Act* (H.R. 2507) renews 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. The legislation, which was reauthorized in 2014 (P.L. 113-240), expires on September 30, 2019.
- Prior to passage of the Newborn Screening Saves Lives Act, 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, all states, the District of Columbia and Puerto Rico screen for at least 29 of the 35 recommended disorders.

## **Key Bill Provisions**

- Reauthorizes Health Resources and Services Administration (HRSA) grants to help states 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 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.
- Reauthorizes the Advisory Committee on Heritable Disorders in Newborns and Children, which provides states with a Recommended Uniform Screening Panel (RUSP) to help ensure every infant is screened for conditions which have a known treatment.
- Directs the National Academy of Science to develop policy recommendations to modernize the nation's newborn screening system.

## **Screening Facts**

- Newborn Screening reaches almost all of the 4 million babies born in the U.S. each 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.