



# Newborn Screening Saves Lives Reauthorization Act of 2019

## Newborn Screening is Key to Early Diagnosis and Intervention for Neuromuscular Conditions

Newborn screening (NBS) is a nationwide public health program that identifies newborns with certain serious and life-threatening genetic diseases that can be treated, and for which early treatment may contribute to better outcomes. The authorization for the nation's NBS program expires in 2019, and Congress must take action to ensure that the every baby in the United State is screened.

The Newborn Screening Saves Lives Reauthorization Act of 2019 is bipartisan legislation sponsored by Representatives Lucille Roybal-Allard (CA-40), Mike Simpson (ID-02), Katherine Clark (MA-05) and Jaime Herrera Beutler (WA-03). This bill reauthorizes:

- The Health Resources and Services Administration grant program that helps states update their NBS programs, improve the follow-up process to ensure that identified infants are receiving the care they need, and educate parents and families on the importance of NBS.
- The Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), which is responsible for content of the conditions on the Recommended Uniform Screening Panel (RUSP). Diseases on the RUSP have been carefully considered through an evidence review process by ACHDNC.
- Centers for Disease Control and Prevention programs that help states track outcomes of NBS identified infants,
- The National Institutes of Health Hunter Kelly Newborn Screening program, which funds promising new treatments and screening tech.

The bill also focuses on the future of NBS by commissioning a National Academy of Medicine report that will make recommendations on how to modernize the screening program and infrastructure.

**MDA encourages every member of Congress to co-sponsor the Newborn Screening Saves Lives Reauthorization Act.**

### Fast Facts: U.S. Newborn Screening Program

- P.L. 110-204 originally established the national NBS program in 2008
- The current authorization expires in 2019
- 12,000 babies are identified each year
- 49 states and D.C. screen for at least 31 of the 35 conditions on the RUSP
- Two neuromuscular conditions are currently on the RUSP
  - Pompe disease (added 2015)
  - Spinal muscular atrophy (added 2018)