



## **Please Enact S. 2158/ H.R. 2507**

### **Reauthorization of the Newborn Screening Saves Lives Act**

Diagnosis through newborn screening saves lives, improves healthcare outcomes, and reduces long term healthcare costs by allowing for detection and intervention at the earliest moment possible.

**Please contact Chairman Lamar Alexander (202-224-4944) and Ranking Member Patty Murray (202-224-2621) to share your support.**

#### **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 Act was first reauthorized in 2014.
- Prior to this act, the number and quality of newborn screening tests varied greatly by state.
- In 2007, only 10 states and the District of Columbia required infants to be screened for all of the recommended disorders. Today, all 50 states and the District of Columbia require screening for at least 31 treatable conditions, as recommended by the Department of Health and Human Services.

#### **Current Status of Bill**

- Federal newborn screening programs expired on September 30, 2019.
- The House has done its job, passing the Newborn Screening Saves Lives Reauthorization Act in July 2019. Currently, the bill is held up in the Senate.
- The Senate bill is held up due to a proposed amendment that would require parents to opt-in to allow their newborn's unidentified dried blood spot (DBS) to be used for research, which would break down the entire newborn screening system.
- Public health laboratories and scientific researchers need DBS to conduct life-saving research to improve the current tests and work to develop new treatments for the thousands of rare diseases still without a cure.
- Complying with this amendment would place a high burden on hospitals that would likely choose not to participate in collection of DBS. Studies have demonstrated that 90%-99% of parents would choose to opt-in, but at times only half of parents would be asked by hospital staff due to the compliance burden.

#### **Key Bill Provisions**

- Reauthorizes the Health Resources and Services Administration (HRSA) state grants to expand and improve screening programs, provide educational resources to parents and health care providers, and improve follow-up care for infants with a detected condition.
- Reauthorizes the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children, which provides states with a Recommended Uniform Screening Panel (RUSP), helping to ensure every infant is screened for conditions that have a known treatment.

*Rare Disease Legislative Advocates (RDLA) is a program of the EveryLife Foundation for Rare Diseases designed to support the advocacy of all rare disease patients and organizations. RDLA is committed to growing the patient advocacy community and working collaboratively, thereby amplifying the patient voice to be heard by local, state, and federal policy makers.*

**Please contact Shannon von Felden ([vonfelden@curetheprocess.org](mailto:vonfelden@curetheprocess.org)) to learn more about RDLA.**

## **Newborn Screening Facts**

- Of the four million babies born in the U.S. each year, one in 300 are found to have a potentially devastating condition through newborn screening.
- 12,000 newborns benefit from the early detection and delivery of life-saving treatments.
- Newborn Screening is the practice of testing every newborn for certain genetic, metabolic, hormonal, and functional conditions that are not otherwise apparent at birth.
- Diagnosis through newborn screening saves lives, improves healthcare outcomes, and reduces long-term healthcare costs by allowing for detection and intervention at the earliest moment possible.
- Newborn screening is the most successful public health program in the history of our country.