

S. 350 – Cosponsor the Newborn Screening Saves Lives Reauthorization Act

MPS diseases are rare genetic diseases that affect both children and adults. They cause progressive damage to cells in the body, resulting in severe disability and early death. There are few treatments and no cures. But there is hope.

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.

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 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.

Status of Bill

- Federal newborn screening programs expired on September 30, 2019.
- The House and Senate both introduced legislation that used the same language to re-authorize and build upon the current federal newborn screening program.
- The House passed the legislation June 23 and the Senate legislation is still pending.
- The legislation has been held up due to a proposed amendment that would require parents to opt-in (with informed consent) to allow their newborn's unidentified dried blood spots to be used for research, which would break down the entire system. Studies show 90%-99% of parents opt-in; but at times only half of the parents are asked by hospital staff due to 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 advises the Secretary of Health and Human Services on newborn and childhood screening policies and priorities to enhance state health agencies to ensure screening is available to every eligible infant. Includes the evidence-based federal Recommended Uniform Screening Panel (RUSP).

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.
- 20,000 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.