



Please Cosponsor H.R. XXXX/ S. XXXX, Reauthorization of the Newborn Screening Saves Lives Act

This bill will reauthorize critical existing federal programs that provide assistance to states to improve and expand their newborn screening programs, support parent and provider education, ensure laboratory quality and effective surveillance. Diagnosis through newborn screening enables early intervention that can reduce the progression of irreversible harm and significantly reduce long term treatment costs.

Please contact Debbie Jessup (Debbie.Jessup@mail.house.gov) in Rep. Roybal-Allard's office to cosponsor this legislation.

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 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 50 states and the District of Columbia require screening for at least 29 treatable conditions, as recommended by the Department of Health and Human Services.

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 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) to help ensure every infant is screened for conditions which have a known treatment.

Newborn Screening Facts

- Newborn screening reaches each of the 4 million babies born in the U.S. every year.
- Approximately 1 in 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.

Rare Disease Legislative Advocates (RDLA), a program of the Everylife Foundation for Rare Diseases, works to empower the individual to become an advocate by providing informational meetings, legislative resources, advocacy tools, and special events that support organizations and advocates working to promote rare disease legislation. RDLA's objective is to grow the patient advocacy community and work collectively to ensure that patients have a voice on Capitol Hill.

Please Shannon von Felden (vonfelden@curetheprocess.org) to learn more about RDLA.