



Please Cosponsor H.R. 2507, the Newborn Screening Saves Lives Reauthorization Act of 2019

Introduced by Representative Lucille Roybal-Allard (D-CA), the Newborn Screening Saves Lives Reauthorization Act will reauthorize critical existing 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 effective surveillance. Diagnosis through newborn screening enables early intervention that can reduce the progression of irreversible harm and significantly reduce long term treatment costs.

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 then 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 of the 35 treatable conditions recommended by the Department of Health and Human Services.

Key Bill Provisions

- Reauthorizes programs at the Health Resources and Services Administration (HRSA), the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH) that help states expand and improve their screening programs, educate parents and health care providers, improve follow-up care for infants with a detected condition, and advance the science of newborn screening.
- 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 almost 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.

The EveryLife Foundation for Rare Diseases is a 501(c)(3) nonprofit dedicated to advancing the development of treatment and diagnostic opportunities for rare disease patients through public policy.



- Dial 1-844-872-0234 and wait for the automated voice machine.
- Press “1” and enter your ZIP code XXXXX. This will connect you to your first senator.

Ask: Please cosponsor the Newborn Screening Saves Lives Reauthorization Act

- Hi! My name is XXXX and I’m calling from [your city/town].
- As a [patient or caregiver] in the rare disease community, I ask that you please cosponsor H.R. 2507, the Newborn Screening Saves Lives Reauthorization Act.
- This legislation will reauthorize 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.
- Without reauthorization, these programs will expire at the end of Fiscal Year 2019.
- Newborn screening detects conditions that, if left untreated, can cause disabilities, developmental delays, illness or even death. If diagnosed early, many of these disorders can be managed successfully and at a lower long-term cost.
- These public health programs were last reauthorized in 2014 with unanimous consent in both the House and Senate. Please stand with the 4 million babies born in the United States each year and cosponsor this legislation.
- Please contact me at [your phone number] or [your email address] to let me know if you will support this effort.
- Thank you for your service and for considering my request.