



SAVE AND IMPROVE LIVES THROUGH NEWBORN SCREENING

Support the Newborn Screening Saves Lives Reauthorization Act and Funding for Federal Newborn Screening Programs

DID YOU KNOW?

- Rare diseases are defined as conditions that impact fewer than 200,000 people in the U.S. Collectively, there are approximately 7,000 rare diseases that affect 30 million Americans. Of the 7,000 rare diseases, only about 5 percent have FDA-approved treatments. ([Source: U.S. Government Accountability Office](#))
- Spinal muscular atrophy (SMA) is an inherited neurodegenerative disease that affects the motor nerve cells in the spinal cord and impacts the muscles used for activities such as breathing, eating, crawling, and walking. SMA impacts 1 in 11,000 births in the U.S. Three FDA-approved treatments for SMA exist that help to slow or stop degeneration associated with SMA. ([Source: Cure SMA](#))
- Early diagnosis and treatment for SMA can lead to improved, long-lasting developmental outcomes for individuals with SMA. In addition, clinical data shows that SMA treatments and care are more effective when delivered early, even before symptoms appear. Newborn screening is the most effective and efficient way for babies with SMA to access timely treatments and available support. ([Source: Cure SMA](#))

WHY CONGRESS SHOULD ACT

Newborn screening is one of the most effective and valued healthcare programs in the United States. Newborn screening saves or improves the lives of nearly 13,000 babies each year, according to the U.S. Department of Health and Human Services ([HHS](#)). Newborns across the country are screened for SMA and other conditions on the Recommended Uniform Screening Panel (RUSP) through state newborn screening programs. Early identification of a RUSP condition allows parents of these children to make timely decisions about treatment and care, which can reduce or prevent serious healthcare complications and service needs. State newborn screening programs have an ongoing need for technical assistance and resources to improve, maintain, and add new conditions to their newborn screening panels.

CURE SMA POSITION

Congress should promote the health and well-being of children, including with SMA, by ensuring continuation of newborn screening programs and activities.

Reauthorize the Newborn Screening Saves Lives Act (P.L. 110-204)

- Extend and improve federal newborn screening activities, including grant programs to help state implement and test newborn screening of new conditions such as SMA.
- Extend the federal advisory committee that reviews new conditions for inclusion on the Recommended Uniform Screening Panel.

Fully fund federal newborn screening programs at the U.S. Department of Health and Human Services

- The Heritable Disorders Programs at HHS's Health Resources and Services Administration supports activities to strengthen the newborn screening system and ensure infants born in every state receive rapid identification, early intervention, and potentially life-saving treatment.
- The Newborn Screening Quality Assurance Program at HHS's Centers for Disease Control and Prevention supports newborn screening efforts so that affected newborns can receive life-saving treatment through the timely implementation for all RUSP conditions.



Cure SMA Advocacy | 800-866-1762 | advocacy@curesma.org | cureSMA.org

[Cure SMA](#) is a national organization that advocates for individuals with spinal muscular atrophy, a progressive neurodegenerative disease that robs people of physical strength, taking away their ability to walk, swallow, and breathe.