



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

Newborn Screening Basic Facts

- Newborn screening is a public health activity used for the early identification of infants affected by certain genetic, metabolic, hormonal and/or functional conditions.
- Screening detects disorders in newborns that, if left untreated, can cause death, disability, mental retardation and other serious illnesses.
- Parents are often unaware that while nearly all babies born in the United States undergo newborn screening the number of disorders for which newborn screening is done the quality of tests vary from state to state.
- If diagnosed early, these conditions can be successfully treated.

In 2008, Congress recognized the need for additional resources dedicated to newborn screening by unanimously approving the Newborn Screening Saves Lives Act (P.L. 110-204). Increased funding, as authorized by this law is needed for HRSA and CDC to expand assistance to state newborn screening programs and to provide quality assurance for laboratories involved in screening newborns for heritable disorders.

Health Resources and Services Administration

The Newborn Screening Coalition recommends establishing a new budget line and providing **\$30 million** in funding to fully implement the Newborn Screening Saves Lives Act. Specifically funds would be available to:

- Enhance, improve or expand the ability of State newborn screening programs to provide screening, counseling or health care services to newborns and children;
- Assist in providing health care professionals with education in newborn screening and training in relevant new technologies;
- Develop and deliver educational programs about newborn screening counseling testing, follow-up, treatment and specialty services to parents, families and patient advocacy and support groups; and
- Establish, maintain and operate a system to assess and coordinate treatment for disorders.

Rationale and Justification:

State and local governments fund newborn screening programs across the country. Due to current budget crises many states are looking to the federal government for assistance to support critical improvements in their newborn screening programs. While the American College of Medical Genetics, the American Academy of Pediatrics, the March of Dimes and the Secretary's Advisory Committee on Heritable Disorders and others recommend screening all newborns for 29 treatable disorders, the list of conditions for which newborns are screened varies by state.

Although newborns are screened and treated for a debilitating condition in one state, in another state, screening may not be required and the undetected condition may result in permanent disability or even death. There is a need for federal guidance and incentives to assist states in improving their newborn screening programs.

Centers for Disease Control and Prevention: The Newborn Screening Coalition recommends providing **\$10 million** to CDC's Newborn Screening Quality Assurance Program (NSQAP). CDC will continue to harness the latest advances in science and technology so that more babies can be detected accurately and treated quickly. Specifically, CDC will:

- Fund state public health laboratories so screening tests are developed, refined and pilot studies conducted for specific disorders, (e.g., Severe Combined Immune Deficiency, Pompe Disease, Metachromatic Leukodystrophy, etc.) presently not included in test panels..
- Develop and provide comprehensive quality assurance services for new tests as they are evaluated in pilot studies and implemented into routine newborn screening practice.

Rationale and Justification

CDC's Environmental Health Laboratory houses the only comprehensive program in the world devoted to ensuring the accuracy of newborn screening tests. Because of the Newborn Screening Quality Assurance Program (NSQAP), parents and doctors can trust the results of newborn screening tests.