



Health Resources and Services Administration Newborn Screening Activities

- Newborn screening is a public health activity used for 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 for some genetic birth defects, the number of disorders for which screening is done and the quality of the tests vary from state to state.
- The March of Dimes, American Academy of Pediatrics and American College of Medical Genetics recommend that, at a minimum, every baby born in the US be screened for a core set of treatable conditions, regardless of the state in which he/she is born. As of March 2008, only 19 states and DC require screening for all 29 treatable disorders.
- If diagnosed early, these conditions can be successfully treated, yet an estimated 1,000 of the 5,000 babies born every year in the United States with one of the 29 'core' conditions potentially go unscreened.



Health Resources and Services Administration [SPRANS]

The March of Dimes **recommends \$4.9 million in funding to enable HRSA to expand its newborn screening program (a \$3 million increase over the FY08 level of \$1.9 million).** Specifically funds would be available to:

- Update and guide states on the disorders for which infants should be screened at birth;
- Help improve states' ability to develop, evaluate, and acquire innovative testing technologies; and
- Increase states' capacity to educate and reach health providers and parents with accurate and up to date information on newborn screening programs and follow-up services.

Rationale and Justification:

State and local governments fund newborn screening programs across the country. Many states use a portion of their Maternal and Child Health Block Grant to support newborn screening programs. While 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.

For more information contact Emil Wigode or Carolyn Mullen, March of Dimes Office of Government Affairs at (202) 659-1800.

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FY09 Recommended Report Language and Funding Levels

| Program | FY08 | FY09 Suggested | Increase |
|----------------------------|-------------|-----------------------|-----------------|
| Newborn Screening [SPRANS] | \$1,921,000 | \$4,921,000 | \$3,000,000 |

Maternal and Child Health Block Grant. — The Committee provides \$4,921,000 to continue the heritable disorders (newborn) screening program. Newborn screening is an essential public health function provided to all newborns in the United States. The Committee is aware that the number of conditions and the quality of programs varies from state to state. The Committee provides increased funding to make it possible for HRSA to guide states by providing current information on the panel of conditions for which infants should be screened and to improve health provider and public education.