



## S. 1858 – Newborn Screening Saves Lives Act of 2007

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### FLOOR SITUATION

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S. 1858 is being considered on the floor under suspension of the rules and will require a two-thirds majority vote for passage. This legislation was introduced by Senator Chris Dodd (D-CT) on July 23, 2007. The Senate passed this legislation by Unanimous Consent on December 13, 2007, and it was referred to the House Committee on Energy and Commerce.

*\*Note: The Committee on Energy and Commerce reported H.R. 3825, companion legislation introduced by Representative Lucille Roybal-Allard (D-CA), on March 13, 2008.*

S. 1858 is expected to be considered on the floor of the House of Representatives on April 8, 2007.

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### SUMMARY

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S. 1858 authorizes the Secretary of Health and Human Services, acting through the Administrator of the Health Resources Services Administration, to award grants to improve, expand, or enhance newborn and child screening for heritable disorders. In addition, the bill requires the Secretary to coordinate programs funded by these grants with existing newborn screening activities.

*Authorization Level: The bill authorizes \$30 million for fiscal year 2009 and incrementally increases each year to \$31.5 million for fiscal year 2012.*

The bill expands the responsibilities of the Advisory Committee on Heritable Disorders in Newborns and Children to include making recommendations regarding heritable disorders that could impact public health for which all newborns should be screened, developing a model decision-matrix for newborn screening expansion, and considering ways to ensure that all States attain the capacity to screen for heritable disorders.

*Authorization Level: The bill authorizes \$1 million for the Advisory Committee for fiscal year 2009 and incrementally each year to \$1.05 million for fiscal year 2012.*

S. 1858 requires the Secretary and the Administrator to establish and maintain a clearinghouse of educational and family support and services information on newborn screening to be available on the Internet to enable parents, family members, health professionals, industry representatives, and the general public to increase their awareness, knowledge, and understanding of newborn screening.

*Authorization Level: This legislation authorizes \$2.5 million for fiscal year 2009 and increases each year to \$2.625 million for fiscal year 2012.*

In addition, the bill requires the Secretary to create an Interagency Coordinating Committee on Newborn and Child Screening. This committee is charged with assessing existing activities and infrastructure in order to make recommendations for programs to collect, analyze, and make available data on heritable disorders, as well as make recommendations for the establishment of regional centers that will conduct research to promote the prevention of poor health outcomes resulting from such disorders.

*Authorization Level: The bill authorizes appropriations for this provision at \$1 million for fiscal year 2009 and the amount increases each year to \$1.05 million in fiscal year 2012.*



This legislation establishes the Hunter Kelly Newborn Screening Research Program at the National Institutes of Health. This new program would carry out, coordinate, and expand research in newborn screening.

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## BACKGROUND

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Newborn screening is used to identify children at increased risk for selected metabolic or genetic diseases. Identifying these risks early and beginning treatment can lead to a reduction in morbidity, mortality, and associated disabilities in affected infants.

Each state determines its own policies and procedures for newborn screening, which can include some or all of the 29 tests available. Currently, every state provides newborn screening for phenylketonuria (PKU) and congenital hypothyroidism.

*\*Note: According to the National Institutes of Health website, "Phenylketonuria (PKU) is a genetic disorder in which the body can't process part of a protein called phenylalanine (Phe). Phe is in almost all foods. If the Phe level gets too high, it can damage the brain and cause severe mental retardation. All babies born in U.S. hospitals must now have a screening test for PKU. This makes it easier to diagnose and treat the problem early."*

According to the Centers for Disease Control and Prevention's website, four million infants are screened in the United States each year and severe disorders are found in approximately 5,000. The CDC goes on to explain that accurate screening ensures that affected babies are identified quickly; cases of disease are not missed; the number of false-positive results is minimized; and early treatment will begin that will prevent negative and irreversible health outcomes for affected newborns.

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## COST

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According to the Congressional Budget Office (CBO) cost estimate, "CBO estimates that the act would authorize the appropriation of \$45 million for 2008 and \$229 million over the 2008-2012 period. Assuming the appropriation of those amounts, CBO estimates that implementing the act would cost \$11 million in 2008 and \$218 million over the 2008-2013 period. S. 1858 would not affect direct spending or revenues." ([CBO Cost Estimate](#))

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## STAFF CONTACT

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For questions or further information contact Brianne Miller at (202) 226-2302.