

Newborn Screening Saves Lives Act (S.1858)

S. 1858 the Newborn Screening Saves Lives Act introduced by Senators Dodd, Clinton Hatch and Kennedy is designed to amend the Public Health Service Act to establish grant programs to provide for education and outreach on newborn screening and coordinate follow up care once newborn screening has been conducted and to reauthorize programs under part A of title XI of the Public Health Service Act.

Improved Newborn and Child Screening for Heritable Disorders. (Sec. 2)

- Authorizes \$15 million in grants in FY08 (and 1% increase each fiscal year through FY12) to enhance, improve or expand the ability of State and local public health agencies newborn screening programs. Also, encourages states to adopt and implement guidelines and recommendations of the Advisory Committee on Heritable Disorders in Newborns and Children.

- Authorizes \$15 million in grants in FY08 (1% increase each fiscal year through FY12)
 - Educate and train health care professionals and state laboratory personnel in newborn screening and relevant new technologies.
 - Educate and inform parents, families and patient advocacy and support groups about newborn screening
 - Establish a coordinated system of follow-up care for newborns and their families after screening and diagnosis.

- Entities eligible for grant funds include: states, territories, health care facility of the Indian Health Service or other entities with appropriate expertise in newborn screening.

Evaluating the Effectiveness of Newborn and Child Screening Programs. (Section 3)

- Authorizes \$5 million in FY08 (and an increase of 1% each fiscal year through FY09-FY12) to evaluate the effectiveness of newborn and child screening programs.

Advisory Committee on Heritable Disorders in Newborns and Children. (Section 4)

- Reauthorizes the Advisory Committee on Heritable Disorders in Newborns and Children for 5 years and authorizes \$1 million in FY08 (and an increase of 1% each fiscal year through FY09-FY12) to provide a uniform screening panel for newborn screening programs that includes secondary conditions that may be identified, develop a decision matrix for newborn screening expansion, consider ways to ensure states attain the capacity to screen for the conditions and periodically update the recommended uniform screening panel.

- Within 180 days the Secretary will adopt or reject the Advisory Committee's recommendations and publicize his determination.

- Produce a report on peer-reviewed newborn screening guidelines, including follow up and treatment.

Information Clearinghouse (Section 5)

- Authorizes \$2.5 million for FY08 (and a 1% increase each fiscal year FY09-FY12) for HRSA in consultation with CDC and NIH to establish and maintain a central clearinghouse of current educational and family support and services information, materials, resources, research and data on newborn screening.

Laboratory Quality and Surveillance. (Section 6)

- Authorizes \$5 million for FY08 (and a 1% increase each fiscal year through FY09-FY12) for the CDC and in consultation with the Advisory Committee to provide quality assurance for newborn screening laboratories and appropriate quality control and other performance test materials to evaluate the performance of new screening tools.
- Authorizes \$1 million in FY08 (and a 1% increase each fiscal year through FY09-FY12) to establish an Interagency Coordinating Committee on Newborn and Child Screening comprised of the CDC, NIH, HRSA and AHRQ to assess current activities and make recommendations for programs to make data available on heritable disorders and make recommendations on the establishment of regional centers to conduct epidemiological research. The Committee will report to Congress and the Secretary on its recommendations.

Contingency Planning (Sec 7)

- Asks CDC, in consultation with HRSA and State departments of Health, to develop a national contingency plan for newborn screening for use by a State, region or consortia of States in the event of a public health emergency.
- The Secretary in conjunction with NIH, and taking into considerations of the Advisory Committee may continue to carry out, coordinate and expand research (to be know as the Hunter Kelly Newborn Screening Research Program) in identifying developing and testing new screening technologies; experimental treatments for conditions that can be detected through newborn screening for which treatment is not yet available and other activities identified by the Director.