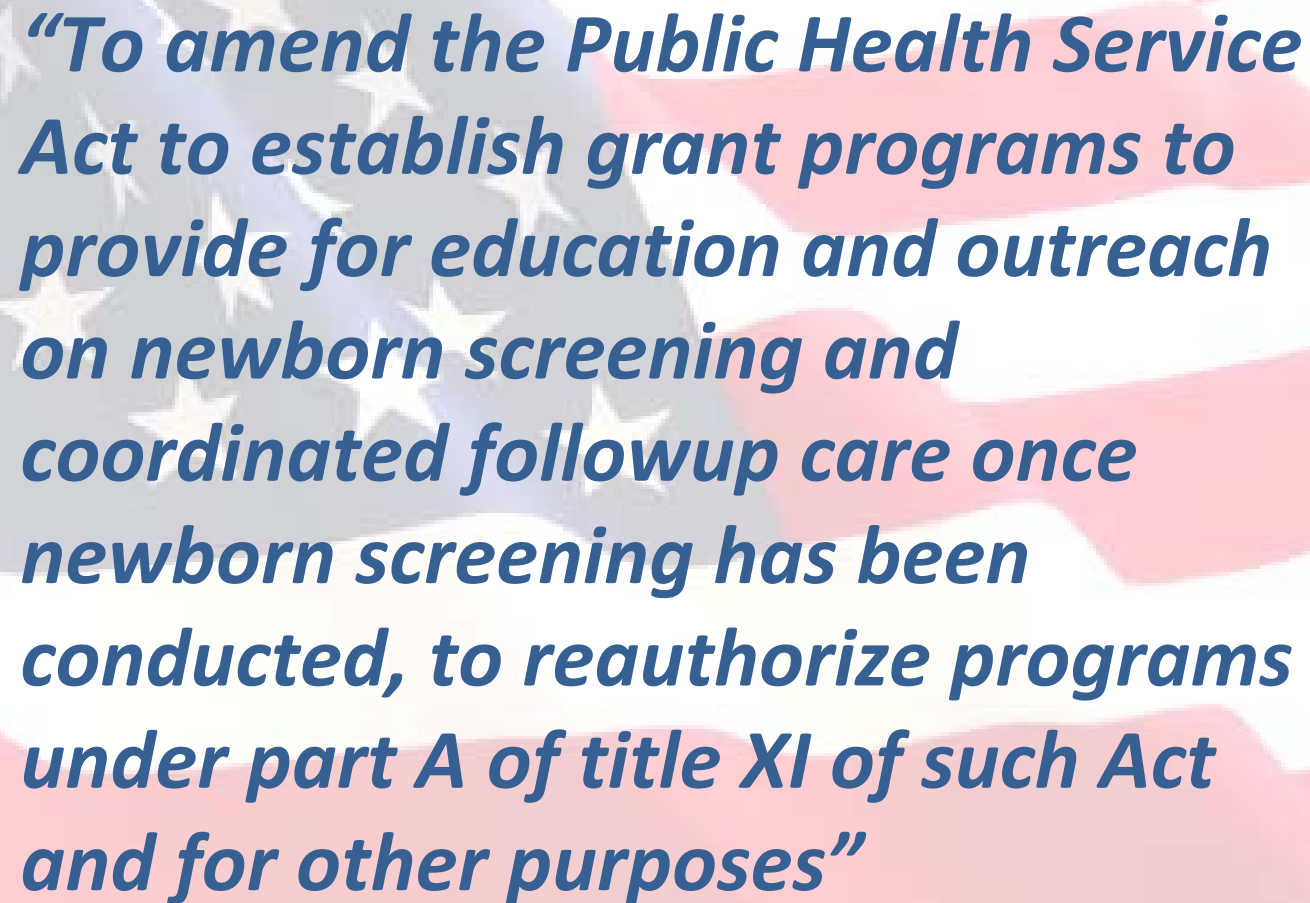


The background of the slide is a stylized, wavy American flag with red and white stripes and a blue field with white stars. The text is centered over this background.

**Newborn Screening  
Saves Lives Act of  
2007**

The background of the slide is a stylized, semi-transparent American flag with its characteristic stars and stripes. The text is overlaid on this background in a dark blue, bold, italicized font.

***“To amend the Public Health Service Act to establish grant programs to provide for education and outreach on newborn screening and coordinated followup care once newborn screening has been conducted, to reauthorize programs under part A of title XI of such Act and for other purposes”***

## **Major Components of the Bill**

- **Provides \$15 mil in grant funding in 08 (with 1% annual increases to 2012) to enhance, improve, or expand state newborn screening programs**
- **Provides 15 mil in 08 (with 1% annual increases to 2012) to educate and inform health care and laboratory professionals, parents, advocacy and support groups about NBS and to establish a coordinated system of follow-up care**
- **Provides \$5 mil in 08 (1% increases to 2012) to evaluate the effectiveness of NBS programs**

# Major Components of the Bill

- Reauthorizes the Secretaries Advisory Committee on Heritable Diseases and provides \$1 mil annually with 1% increases
- Charges Sec. Committee with duty to provides a uniform panels that includes secondary conditions ; consider ways to ensure that states attain the capacity to screen for the conditions and to recommend periodic updates to the uniform panel
- Requires Secretary to take prompt action on the committee's recommendations

## **Major Components of the Bill**

- **Provides \$2.5 mil in 08 (with 1% annual increases) for HRSA, in consultation with CDC and NIH, to establish and maintain a central clearinghouse for educational materials, family support resources, and data and research on NBS. This information must be available online.**
- **Provides \$2.5 mil in 08 (with 1% annual increases) for the CDC in consultation with the Sec. Advisory committee to provide QA/QC tools to evaluate the state programs**

# Major Components of the Bill

- Provides \$1 mil in 08 (with 1% annual increases) to establish an interagency coordinating council of CDC, NIH, HRSA and AHRQ to assess NBS activities of the states and make recommendations for the programs and to conduct research
- Asks the CDC with HRSA and the State programs to develop emergency contingency plans
- Allows HRSA with NIH to conduct research into new screening technologies and new treatments for heritable disorders (unfunded), to be known as the Hunter Kelly Newborn Screening Research Center

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# Reaction

- **Finally requires a uniform panel for tests across the nation eliminating state to state disparities in NBS screens**
- **Puts as much emphasis on what happens after screening as the screen itself, most especially all follow-up activities**
- **Gives strong financial incentives for states to bring their programs up to national standards**
- **Gives more power to the Secretary's Advisory Committee to make policy and to help states implement programs that meet national standards**

The background of the slide is a stylized, semi-transparent American flag with stars and stripes. The title 'Reaction' is centered at the top in a bold, dark blue font.

# Reaction

- **Will help states deal with natural disasters and other emergency situations**
- **Creates an unfunded program for research into new technologies and better treatments**
- **Ties all funding to compliance with national screening program standards as set forth by the Sec. Advisory committee**

# Thank you to all who helped pass this monumental bill!

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