

UNIVERSAL NEWBORN SCREENING

Screening newborns for certain congenital, genetic, and metabolic disorders can lead to the early identification and treatment of serious neurological conditions. Early detection can prevent severe disability or death in infants with these rare illnesses.

The Problem

Every year newborn screening leads to identification and treatment for an estimated 4,000 infants. Though nearly all children born in the US undergo some screening, the extent and quality of tests vary from state to state. Fewer than half the states routinely test for the full recommended panel of 29 disorders for which effective treatment is available. Depending on the screening done in the state of birth, a child with a given disorder may or may not receive treatment in time to prevent life-long disability or death.

The Newborn Screening Lives Act of 2007 (S. 1568)

The Newborn Screening Lives Act of 2007, S. 1568, was passed by unanimous consent in the Senate on December 13, 2007. This legislation would:

- Authorize \$15 million for grants to educate health care professionals and families about newborn screening and establish a coordinated support system following diagnosis.
- Authorize \$25 million to states to expand and improve their newborn screening programs and encourage states to test for the full panel of disorders recommended by the Advisory Committee on Heritable Disorders in Newborns and Children.
- Reauthorize and expand the role of the Advisory Committee to continuously revise and update the panel of recommended tests.
- Require the Centers for Disease Control and Prevention to ensure the quality of laboratories involved in newborn screening.
- Authorize \$15 million to establish a system for collecting and analyzing data from newborn screening programs to help researchers develop a better understanding of the disorders detected by newborn screening and how they might be better detected, prevented, treated, and cured.

What Should Congress Do?

- Pass legislation S. 1568 to increase resources for states to expand their newborn screening programs.

GENETIC NON-DISCRIMINATION

The Problem

Research gains have led to the availability of increasingly advanced genetic tests that can be used for the medical diagnosis and treatment of individuals. The results of such tests may, however, leave diagnosed individuals vulnerable to discrimination.

Genetic Information Nondiscrimination Act of 2007 (S. 358/H.R. 493)

The Genetic Information Nondiscrimination Act of 2007 (S. 358/H.R. 493) would protect individuals from penalization by insurance carriers or employers because of genetic information. The House of Representatives passed H.R. 493 by a vote of 420 to 3 on April 25, 2007.

What Should Congress Do?

- Pass legislation (S. 358/H.R. 493) to ensure that genetic information is not used as the basis for discrimination in both health insurance coverage and employment.

