

S 1417

Newborn Screening Saves Lives Reauthorization Act of 2013

Congress: 113 (2013–2015, Ended)

Chamber: Senate

Policy Area: Health

Introduced: Aug 1, 2013

Current Status: Referred to the Subcommittee on Health.

Latest Action: Referred to the Subcommittee on Health. (Feb 7, 2014)

Official Text: <https://www.congress.gov/bill/113th-congress/senate-bill/1417>

Sponsor

Name: Sen. Hagan, Kay R. [D-NC]

Party: Democratic • **State:** NC • **Chamber:** Senate

Cosponsors (17 total)

Cosponsor	Party / State	Role	Date Joined
Sen. Hatch, Orrin G. [R-UT]	R · UT		Aug 1, 2013
Sen. Casey, Robert P., Jr. [D-PA]	D · PA		Sep 12, 2013
Sen. Enzi, Michael B. [R-WY]	R · WY		Sep 12, 2013
Sen. Collins, Susan M. [R-ME]	R · ME		Sep 26, 2013
Sen. Schumer, Charles E. [D-NY]	D · NY		Sep 26, 2013
Sen. Cochran, Thad [R-MS]	R · MS		Sep 30, 2013
Sen. Bennet, Michael F. [D-CO]	D · CO		Oct 28, 2013
Sen. Cantwell, Maria [D-WA]	D · WA		Oct 28, 2013
Sen. Donnelly, Joe [D-IN]	D · IN		Oct 28, 2013
Sen. Murphy, Christopher [D-CT]	D · CT		Oct 28, 2013
Sen. Schatz, Brian [D-HI]	D · HI		Oct 28, 2013
Sen. Franken, Al [D-MN]	D · MN		Dec 11, 2013
Sen. Harkin, Tom [D-IA]	D · IA		Dec 18, 2013
Sen. Wicker, Roger F. [R-MS]	R · MS		Dec 19, 2013
Sen. Alexander, Lamar [R-TN]	R · TN		Jan 16, 2014
Sen. Shaheen, Jeanne [D-NH]	D · NH		Jan 16, 2014
Sen. Burr, Richard [R-NC]	R · NC		Sep 11, 2014

Committee Activity

Committee	Chamber	Activity	Date
Energy and Commerce Committee	House	Referred to	Feb 7, 2014
Health, Education, Labor, and Pensions Committee	Senate	Reported By	Dec 19, 2013

Subjects & Policy Tags

Policy Area:

Health

Related Bills

No related bills are listed.

(This measure has not been amended since it was reported to the Senate on December 19, 2013. The summary of that version is repeated here.)

Newborn Screening Saves Lives Reauthorization Act of 2013 - (Sec. 2) Amends the Public Health Service Act to extend through FY2018 a grant program for newborn and child screening programs for heritable disorders. Includes the improvement of the timely collection, delivery, and receipts, and screening of specimens, and the timely diagnosis of heritable disorders in newborns as a permissible use of grant funds.

(Sec. 3) Extends through FY2018 a demonstration program to evaluate the effectiveness of screening, follow-up, counseling or health care services in reducing the morbidity and mortality caused by heritable disorders in newborn and children. Permits the program to also evaluate and assess: (1) methods to improve quality in the diagnosis, treatment, and disease management of heritable disorders based on gaps in services or care; and (2) methods or best practices by which states or political subdivisions of a state, territories, Indian health care facilities or programs, or any entity with appropriate expertise in newborn screening can achieve the timely collection, delivery, receipt, and screening of newborn screening specimens, and the timely diagnosis of heritable disorders in newborns.

(Sec. 4) Reauthorizes through FY2018 and extends for five years the operation of the Advisory Committee on Heritable Disorders in Newborns and Children. Expands the duties of the Advisory Committee to include providing technical assistance to individuals and organizations regarding the submission of nominations to the uniform screening panel. Requires the Advisory Committee to give recommendations, advice, or information to the Secretary of Health and Human Services (HHS) on the timely collection, delivery, receipt, and screening of specimens to be tested for heritable disorders in newborns.

Revises the process for the Secretary to consider the Advisory Committee's recommendations.

Requires the Advisory Committee to meet at least four times per year.

(Sec. 5) Extends through FY2018 the Newborn Screening Clearinghouse of current education and family support and services information, materials, resources, research, and data on newborn screening.

(Sec. 6) Extends through FY2018 a quality assurance program requiring the Secretary, acting through the Director of the Centers for Disease Control and Prevention (CDC), to provide for quality assurance of laboratories involved in screening for heritable disorders. Authorizes the Secretary, acting through the Director, to also provide for the coordination of surveillance activities.

(Sec. 7) Makes the Interagency Coordinating Committee on Newborn and Child Screening permanent. Includes the Commissioner of Food and Drugs (FDA) as a member of the Interagency Committee.

(Sec. 8) Requires the national contingency plan for newborn screening to be updated at least every five years.

(Sec. 9) Allows the expansion of the Hunter Kelly Newborn Screening Research Program to include: (1) providing research findings and data for newborn conditions under review by the Advisory Committee to be added to the recommended uniform screening panel, and (2) conducting pilot studies on conditions recommended by the Advisory Committee to ensure that the screenings are ready for nationwide implementation.

(Sec. 11) Requires the Comptroller General to report to the relevant congressional committees on the timeliness of

screening for heritable disorders in newborns.

Requires the Secretary to report to the relevant congressional committees biennially on activities related to newborn screening and screening children who have or are at risk for heritable disorders.

Actions Timeline

- **Feb 7, 2014:** Referred to the Subcommittee on Health.
- **Jan 31, 2014:** Received in the House.
- **Jan 31, 2014:** Referred to the House Committee on Energy and Commerce.
- **Jan 30, 2014:** Message on Senate action sent to the House.
- **Jan 29, 2014:** Passed/agreed to in Senate: Passed Senate with an amendment by Unanimous Consent.(consideration: CR S605-607; text as passed Senate: CR S605-607)
- **Jan 29, 2014:** Passed Senate with an amendment by Unanimous Consent. (consideration: CR S605-607; text as passed Senate: CR S605-607)
- **Dec 19, 2013:** Committee on Health, Education, Labor, and Pensions. Reported with an amendment in the nature of a substitute. Without written report.
- **Dec 19, 2013:** Placed on Senate Legislative Calendar under General Orders. Calendar No. 282.
- **Dec 18, 2013:** Committee on Health, Education, Labor, and Pensions. Ordered to be reported with an amendment in the nature of a substitute favorably.
- **Aug 1, 2013:** Introduced in Senate
- **Aug 1, 2013:** Read twice and referred to the Committee on Health, Education, Labor, and Pensions.