

HR 1281

Newborn Screening Saves Lives Reauthorization Act of 2014

Congress: 113 (2013–2015, Ended)

Chamber: House

Policy Area: Health

Introduced: Mar 20, 2013

Current Status: Became Public Law No: 113-240.

Latest Action: Became Public Law No: 113-240. (Dec 18, 2014)

Law: 113-240 (Enacted Dec 18, 2014)

Official Text: <https://www.congress.gov/bill/113th-congress/house-bill/1281>

Sponsor

Name: Rep. Roybal-Allard, Lucille [D-CA-40]

Party: Democratic • **State:** CA • **Chamber:** House

Cosponsors (120 total)

Cosponsor	Party / State	Role	Date Joined
Rep. Simpson, Michael K. [R-ID-2]	R · ID		Mar 20, 2013
Rep. Grijalva, Raúl M. [D-AZ-3]	D · AZ		Mar 21, 2013
Rep. Moore, Gwen [D-WI-4]	D · WI		Mar 21, 2013
Rep. Waxman, Henry A. [D-CA-33]	D · CA		Mar 25, 2013
Rep. Rogers, Harold [R-KY-5]	R · KY		Apr 15, 2013
Rep. Higgins, Brian [D-NY-26]	D · NY		Apr 26, 2013
Rep. Bishop, Sanford D., Jr. [D-GA-2]	D · GA		May 6, 2013
Rep. Capps, Lois [D-CA-24]	D · CA		May 6, 2013
Rep. Castor, Kathy [D-FL-14]	D · FL		May 6, 2013
Rep. Clarke, Yvette D. [D-NY-9]	D · NY		May 6, 2013
Rep. Cohen, Steve [D-TN-9]	D · TN		May 6, 2013
Rep. Conyers, John, Jr. [D-MI-13]	D · MI		May 6, 2013
Rep. Crowley, Joseph [D-NY-14]	D · NY		May 6, 2013
Rep. DeLauro, Rosa L. [D-CT-3]	D · CT		May 6, 2013
Rep. Dingell, John D. [D-MI-12]	D · MI		May 6, 2013
Rep. Hastings, Alcee L. [D-FL-20]	D · FL		May 6, 2013
Rep. Huffman, Jared [D-CA-2]	D · CA		May 6, 2013
Rep. Jackson Lee, Sheila [D-TX-18]	D · TX		May 6, 2013
Rep. Lee, Barbara [D-CA-13]	D · CA		May 6, 2013
Rep. Loebsack, David [D-IA-2]	D · IA		May 6, 2013
Rep. McCollum, Betty [D-MN-4]	D · MN		May 6, 2013
Rep. McGovern, James P. [D-MA-2]	D · MA		May 6, 2013
Rep. Rangel, Charles B. [D-NY-13]	D · NY		May 6, 2013
Rep. Scott, David [D-GA-13]	D · GA		May 6, 2013
Rep. Slaughter, Louise McIntosh [D-NY-25]	D · NY		May 6, 2013
Rep. Speier, Jackie [D-CA-14]	D · CA		May 6, 2013
Rep. Takano, Mark [D-CA-41]	D · CA		May 6, 2013
Rep. Wilson, Frederica S. [D-FL-24]	D · FL		May 6, 2013
Rep. Bera, Ami [D-CA-7]	D · CA		May 14, 2013
Rep. Walden, Greg [R-OR-2]	R · OR		May 14, 2013
Rep. Green, Gene [D-TX-29]	D · TX		Jun 3, 2013
Rep. Nadler, Jerrold [D-NY-10]	D · NY		Jun 3, 2013
Rep. Collins, Chris [R-NY-27]	R · NY		Jun 11, 2013
Rep. Delaney, John K. [D-MD-6]	D · MD		Jun 11, 2013
Rep. Farr, Sam [D-CA-20]	D · CA		Jun 11, 2013
Rep. Heck, Denny [D-WA-10]	D · WA		Jun 11, 2013
Rep. Pocan, Mark [D-WI-2]	D · WI		Jun 11, 2013
Rep. Matheson, Jim [D-UT-4]	D · UT		Jul 8, 2013
Rep. Beatty, Joyce [D-OH-3]	D · OH		Jul 24, 2013
Rep. Kirkpatrick, Ann [D-AZ-1]	D · AZ		Jul 30, 2013
Rep. Moran, James P. [D-VA-8]	D · VA		Sep 9, 2013

Cosponsor	Party / State	Role	Date Joined
Del. Sablan, Gregorio Kilili Camacho [D-MP-At Large]	D · MP		Sep 19, 2013
Rep. Becerra, Xavier [D-CA-34]	D · CA		Sep 19, 2013
Rep. Cárdenas, Tony [D-CA-29]	D · CA		Sep 19, 2013
Rep. Castro, Joaquin [D-TX-20]	D · TX		Sep 19, 2013
Rep. Costa, Jim [D-CA-16]	D · CA		Sep 19, 2013
Rep. Gallego, Pete P. [D-TX-23]	D · TX		Sep 19, 2013
Rep. Garcia, Joe [D-FL-26]	D · FL		Sep 19, 2013
Rep. Gutierrez, Luis V. [D-IL-4]	D · IL		Sep 19, 2013
Rep. Hinojosa, Ruben [D-TX-15]	D · TX		Sep 19, 2013
Rep. King, Peter T. [R-NY-2]	R · NY		Sep 19, 2013
Rep. Lujan Grisham, Michelle [D-NM-1]	D · NM		Sep 19, 2013
Rep. Lujan, Ben Ray [D-NM-3]	D · NM		Sep 19, 2013
Rep. Napolitano, Grace F. [D-CA-32]	D · CA		Sep 19, 2013
Rep. Negrete McLeod, Gloria [D-CA-35]	D · CA		Sep 19, 2013
Rep. Ruiz, Raul [D-CA-36]	D · CA		Sep 19, 2013
Rep. Ryan, Tim [D-OH-13]	D · OH		Sep 19, 2013
Rep. Sanchez, Loretta [D-CA-46]	D · CA		Sep 19, 2013
Rep. Schakowsky, Janice D. [D-IL-9]	D · IL		Sep 19, 2013
Rep. Serrano, Jose E. [D-NY-15]	D · NY		Sep 19, 2013
Rep. Sires, Albio [D-NJ-8]	D · NJ		Sep 19, 2013
Rep. Vargas, Juan [D-CA-51]	D · CA		Sep 19, 2013
Rep. Velazquez, Nydia M. [D-NY-7]	D · NY		Sep 19, 2013
Rep. Calvert, Ken [R-CA-42]	R · CA		Sep 23, 2013
Rep. Capito, Shelley Moore [R-WV-2]	R · WV		Sep 23, 2013
Rep. Royce, Edward R. [R-CA-39]	R · CA		Sep 23, 2013
Rep. Esty, Elizabeth H. [D-CT-5]	D · CT		Sep 25, 2013
Rep. Grayson, Alan [D-FL-9]	D · FL		Sep 25, 2013
Rep. Miller, Gary G. [R-CA-31]	R · CA		Sep 25, 2013
Rep. Barton, Joe [R-TX-6]	R · TX		Sep 28, 2013
Rep. Davis, Danny K. [D-IL-7]	D · IL		Sep 28, 2013
Rep. DeGette, Diana [D-CO-1]	D · CO		Sep 28, 2013
Rep. Doyle, Michael F. [D-PA-14]	D · PA		Sep 28, 2013
Rep. Eshoo, Anna G. [D-CA-18]	D · CA		Sep 28, 2013
Rep. Garamendi, John [D-CA-3]	D · CA		Sep 28, 2013
Rep. Jones, Walter B., Jr. [R-NC-3]	R · NC		Sep 28, 2013
Rep. Langevin, James R. [D-RI-2]	D · RI		Sep 28, 2013
Rep. Lowey, Nita M. [D-NY-17]	D · NY		Sep 28, 2013
Rep. McKeon, Howard P. "Buck" [R-CA-25]	R · CA		Sep 28, 2013
Rep. Neal, Richard E. [D-MA-1]	D · MA		Sep 28, 2013
Rep. Schiff, Adam B. [D-CA-28]	D · CA		Sep 28, 2013
Rep. Tonko, Paul [D-NY-20]	D · NY		Sep 28, 2013
Rep. Wasserman Schultz, Debbie [D-FL-23]	D · FL		Sep 28, 2013

Cosponsor	Party / State	Role	Date Joined
Resident Commissioner Pierluisi, Pedro R. [D-PR-At Large]	D · PR		Sep 28, 2013
Rep. Cicilline, David N. [D-RI-1]	D · RI		Oct 11, 2013
Rep. Courtney, Joe [D-CT-2]	D · CT		Oct 11, 2013
Rep. Levin, Sander M. [D-MI-9]	D · MI		Oct 11, 2013
Rep. McDermott, Jim [D-WA-7]	D · WA		Oct 11, 2013
Rep. Nunes, Devin [R-CA-22]	R · CA		Oct 11, 2013
Rep. Blumenauer, Earl [D-OR-3]	D · OR		Oct 23, 2013
Rep. Titus, Dina [D-NV-1]	D · NV		Oct 23, 2013
Rep. Welch, Peter [D-VT-At Large]	D · VT		Oct 23, 2013
Rep. Lipinski, Daniel [D-IL-3]	D · IL		Oct 24, 2013
Rep. Granger, Kay [R-TX-12]	R · TX		Oct 30, 2013
Rep. Larson, John B. [D-CT-1]	D · CT		Oct 30, 2013
Rep. Matsui, Doris O. [D-CA-6]	D · CA		Oct 30, 2013
Rep. Tierney, John F. [D-MA-6]	D · MA		Oct 30, 2013
Rep. Latham, Tom [R-IA-3]	R · IA		Nov 12, 2013
Del. Christensen, Donna M. [D-VI-At Large]	D · VI		Nov 21, 2013
Rep. Ellison, Keith [D-MN-5]	D · MN		Dec 11, 2013
Rep. Honda, Michael M. [D-CA-17]	D · CA		Dec 11, 2013
Rep. Lance, Leonard [R-NJ-7]	R · NJ		Dec 11, 2013
Rep. Shea-Porter, Carol [D-NH-1]	D · NH		Jan 7, 2014
Rep. Brownley, Julia [D-CA-26]	D · CA		Jan 10, 2014
Rep. Edwards, Donna F. [D-MD-4]	D · MD		Jan 10, 2014
Rep. Meeks, Gregory W. [D-NY-5]	D · NY		Jan 10, 2014
Rep. Michaud, Michael H. [D-ME-2]	D · ME		Jan 10, 2014
Rep. Johnson, Eddie Bernice [D-TX-30]	D · TX		Jan 15, 2014
Rep. Pallone, Frank, Jr. [D-NJ-6]	D · NJ		Jan 15, 2014
Rep. Payne, Donald M., Jr. [D-NJ-10]	D · NJ		Jan 15, 2014
Rep. Johnson, Henry C. "Hank," Jr. [D-GA-4]	D · GA		Jan 28, 2014
Rep. Lowenthal, Alan S. [D-CA-47]	D · CA		Jan 28, 2014
Rep. Clay, Wm. Lacy [D-MO-1]	D · MO		Feb 3, 2014
Rep. Thompson, Mike [D-CA-5]	D · CA		Feb 3, 2014
Rep. Cartwright, Matt [D-PA-17]	D · PA		Feb 6, 2014
Rep. Schwartz, Allyson Y. [D-PA-13]	D · PA		Feb 11, 2014
Rep. Pascrell, Bill, Jr. [D-NJ-9]	D · NJ		Mar 25, 2014
Rep. Burgess, Michael C. [R-TX-26]	R · TX		Apr 3, 2014
Rep. McMorris Rodgers, Cathy [R-WA-5]	R · WA		Apr 3, 2014
Rep. Israel, Steve [D-NY-3]	D · NY		Apr 7, 2014

Committee Activity

Committee	Chamber	Activity	Date
Energy and Commerce Committee	House	Reported by	Feb 27, 2014

Subjects & Policy Tags

Policy Area:

Health

Related Bills

No related bills are listed.

(This measure has not been amended since it was passed by the Senate on December 8, 2014. The summary of that version is repeated here.)

Newborn Screening Saves Lives Reauthorization Act of 2014 - (Sec. 2) Amends the Public Health Service Act to revise and extend through FY2019 a grant program for screening, counseling, and other services related to heritable disorders that can be detected in newborns. Allows grants to be used to improve timeliness of newborn screening and provide training to health care professionals on the importance of timely screening and on the sharing of medical and diagnostic information with providers and families.

(Sec. 3) Extends through FY2019 a grant program to evaluate the effectiveness of screening, counseling, or health care services in reducing the morbidity and mortality caused by heritable disorders in newborns and children. Expands the program to include evaluation of health outcomes through adolescence and best practices for timely screening of newborns.

(Sec. 4) Extends for five years the operation of the Advisory Committee on Heritable Disorders in Newborns and Children. Authorizes the Secretary of Health and Human Services (HHS) to continue the Advisory Committee after such time.

(Sec. 5) Extends through FY2019 the clearinghouse for newborn screening information. Expands the duties of the clearinghouse to include: (1) maintaining current information on the number of conditions for which screening is conducted in each state; and (2) disseminating guidelines for diagnosis, counseling, and treatment of conditions detected by newborn screening.

(Sec. 6) Extends through FY2019 requirements for the Director of the Centers for Disease Control and Prevention (CDC) to provide for quality assurance of laboratories involved in screening newborns and children for heritable disorders. Authorizes the Director to coordinate surveillance activities, including through standardized data collection and reporting and electronic health records.

(Sec. 7) Makes permanent the Interagency Coordinating Committee on Newborn and Child Screening. Adds the Administrator of the Health Resources and Services Administration and the Commissioner of Food and Drugs (FDA) to this committee.

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

(Sec. 9) Authorizes the Secretary to expand the Hunter Kelly Newborn Screening Research Program to: (1) provide research and data for newborn conditions under review by the Advisory Committee to be added to the Recommended Uniform Screening Panel, and (2) conduct pilot studies on conditions recommended by the Advisory Committee to ensure that screenings are ready for nationwide implementation.

(Sec. 11) Requires the Comptroller General (GAO) to report on the timeliness of newborn screening. Requires the Secretary to report on newborn screening activities and expenditures.

(Sec. 12) Directs HHS to update the Federal Policy for the Protection of Human Subjects, also known as the Common Rule, not later than two years after enactment of this Act. Applies the following provisions until HHS updates the Common Rule:

requires federally funded research on newborn dried blood spots to be considered research on human subjects (which requires the informed consent of the subject), and

- eliminates the ability of an institutional review board to waive informed consent requirements for research on newborn dried blood spots.

Actions Timeline

- **Dec 18, 2014:** Signed by President.
- **Dec 18, 2014:** Became Public Law No: 113-240.
- **Dec 12, 2014:** Presented to President.
- **Dec 10, 2014:** Mrs. Ellmers asked unanimous consent that the House agree to the Senate amendment. (consideration: CR H8994-8998)
- **Dec 10, 2014:** Resolving differences -- House actions: On motion that the House agree to the Senate amendment Agreed to without objection.(text as House agreed to Senate amendment: CR H8994-8998)
- **Dec 10, 2014:** On motion that the House agree to the Senate amendment Agreed to without objection. (text as House agreed to Senate amendment: CR H8994-8998)
- **Dec 10, 2014:** Motion to reconsider laid on the table Agreed to without objection.
- **Dec 9, 2014:** Message on Senate action sent to the House.
- **Dec 8, 2014:** Measure laid before Senate by unanimous consent. (consideration: CR S6395)
- **Dec 8, 2014:** Passed/agreed to in Senate: Passed Senate with an amendment by Unanimous Consent.
- **Dec 8, 2014:** Passed Senate with an amendment by Unanimous Consent.
- **Jun 25, 2014:** Received in the Senate, read twice.
- **Jun 24, 2014:** Mr. Pitts moved to suspend the rules and pass the bill, as amended.
- **Jun 24, 2014:** Considered under suspension of the rules. (consideration: CR H5696-5699)
- **Jun 24, 2014:** DEBATE - The House proceeded with forty minutes of debate on H.R. 1281.
- **Jun 24, 2014:** Passed/agreed to in House: On motion to suspend the rules and pass the bill, as amended Agreed to by voice vote.(text: CR H5696-5697)
- **Jun 24, 2014:** On motion to suspend the rules and pass the bill, as amended Agreed to by voice vote. (text: CR H5696-5697)
- **Jun 19, 2014:** Reported (Amended) by the Committee on Energy and Commerce. H. Rept. 113-478.
- **Jun 19, 2014:** Placed on the Union Calendar, Calendar No. 354.
- **Apr 3, 2014:** Committee Consideration and Mark-up Session Held.
- **Apr 3, 2014:** Ordered to be Reported (Amended) by Unanimous Consent.
- **Feb 27, 2014:** Subcommittee Consideration and Mark-up Session Held.
- **Feb 27, 2014:** Forwarded by Subcommittee to Full Committee (Amended) by Voice Vote .
- **Mar 22, 2013:** Referred to the Subcommittee on Health.
- **Mar 20, 2013:** Introduced in House
- **Mar 20, 2013:** Sponsor introductory remarks on measure. (CR H1643)
- **Mar 20, 2013:** Referred to the House Committee on Energy and Commerce.