

SCARLETT'S SUNSHINE ON SUDDEN UNEXPECTED DEATH
ACT

SEPTEMBER 21, 2020.—Committed to the Committee of the Whole House on the
State of the Union and ordered to be printed

Mr. PALLONE, from the Committee on Energy and Commerce,
submitted the following

R E P O R T

[To accompany H.R. 2271]

[Including cost estimate of the Congressional Budget Office]

The Committee on Energy and Commerce, to whom was referred the bill (H.R. 2271) to amend the Public Health Service Act to improve the health of children and help better understand and enhance awareness about unexpected sudden death in early life, having considered the same, reports favorably thereon with an amendment and recommends that the bill as amended do pass.

CONTENTS

	Page
I. Purpose and Summary	4
II. Background and Need for the Legislation	4
III. Committee Hearings	6
IV. Committee Consideration	6
V. Committee Votes	6
VI. Oversight Findings	7
VII. New Budget Authority, Entitlement Authority, and Tax Expenditures	7
VIII. Congressional Budget Office Estimate	7
IX. Federal Mandates Statement	9
X. Statement of General Performance Goals and Objectives	9
XI. Duplication of Federal Programs	9
XII. Committee Cost Estimate	9
XIII. Earmarks, Limited Tax Benefits, and Limited Tariff Benefits	9
XIV. Advisory Committee Statement	9
XV. Applicability to Legislative Branch	9
XVI. Section-by-Section Analysis of the Legislation	9
XVII. Changes in Existing Law Made by the Bill, as Reported	11

The amendment is as follows:
Strike all after the enacting clause and insert the following:

SECTION 1. SHORT TITLE.

This Act may be cited as the “Scarlett’s Sunshine on Sudden Unexpected Death Act”.

SEC. 2. ADDRESSING SUDDEN UNEXPECTED INFANT DEATH AND SUDDEN UNEXPECTED DEATH IN CHILDHOOD.

Part B of title XI of the Public Health Service Act (42 U.S.C. 241 et seq.) is amended—

(1) in the part heading, by striking “SUDDEN INFANT DEATH SYNDROME” and inserting “SUDDEN UNEXPECTED INFANT DEATH, SUDDEN INFANT DEATH SYNDROME, AND SUDDEN UNEXPECTED DEATH IN CHILDHOOD”; and

(2) by inserting before section 1122 the following:

“SEC. 1121. ADDRESSING SUDDEN UNEXPECTED INFANT DEATH AND SUDDEN UNEXPECTED DEATH IN CHILDHOOD.

“(a) IN GENERAL.—The Secretary may develop, support, or maintain programs or activities to address sudden unexpected infant death and sudden unexpected death in childhood, including by—

“(1) continuing to support the Sudden Unexpected Infant Death and Sudden Death in the Young Case Registry of the Centers for Disease Control and Prevention and other fatality case reporting systems that include data pertaining to sudden unexpected infant death and sudden unexpected death in childhood, as appropriate, including such systems supported by the Health Resources and Services Administration, in order to—

“(A) increase the number of States and jurisdictions participating in such systems; or

“(B) improve the utility of such systems, which may include—

“(i) making summary data available to the public in a timely manner on the internet website of the Department of Health and Human Services, in a manner that, at a minimum, protects personal privacy to the extent required by applicable Federal and State law; and

“(ii) making the data submitted to such systems available to researchers, in a manner that, at a minimum, protects personal privacy to the extent required by applicable Federal and State law; and

“(2) awarding grants or cooperative agreements to States, Indian Tribes, and Tribal organizations for purposes of—

“(A) supporting fetal and infant mortality and child death review programs for sudden unexpected infant death and sudden unexpected death in childhood, including by establishing such programs at the local level;

“(B) improving data collection related to sudden unexpected infant death and sudden unexpected death in childhood, including by—

“(i) improving the completion of death scene investigations and comprehensive autopsies that include a review of clinical history and circumstances of death with appropriate ancillary testing; and

“(ii) training medical examiners, coroners, death scene investigators, law enforcement personnel, emergency medical technicians, paramedics, emergency department personnel, and others who perform death scene investigations with respect to the deaths of infants and children, as appropriate;

“(C) identifying, developing, and implementing best practices to reduce or prevent sudden unexpected infant death and sudden unexpected death in childhood, including practices to reduce sleep-related infant deaths;

“(D) increasing the voluntary inclusion, in fatality case reporting systems established for the purpose of conducting research on sudden unexpected infant death and sudden unexpected death in childhood, of samples of tissues or genetic materials from autopsies that have been collected pursuant to Federal or State law; or

“(E) disseminating information and materials to health care professionals and the public on risk factors that contribute to sudden unexpected infant death and sudden unexpected death in childhood, which may include information on risk factors that contribute to sleep-related sudden unexpected infant death or sudden unexpected death in childhood.

“(b) APPLICATION.—To be eligible to receive a grant or cooperative agreement under subsection (a)(2), a State, Indian Tribe, or Tribal organization shall submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require, including information on how such State will ensure activities conducted under this section are coordinated with other federally-funded programs to reduce infant mortality, as appropriate.

“(c) TECHNICAL ASSISTANCE.—The Secretary shall provide technical assistance to States, Tribes, and Tribal organizations receiving a grant or cooperative agreement

under subsection (a)(2) for purposes of carrying out activities funded through the grant or cooperative agreement.

“(d) REPORTING FORMS.—

“(1) IN GENERAL.—The Secretary shall, as appropriate, encourage the use of sudden unexpected infant death and sudden unexpected death in childhood reporting forms developed in collaboration with the Centers for Disease Control and Prevention to improve the quality of data submitted to the Sudden Unexpected Infant Death and Sudden Death in the Young Case Registry, and other fatality case reporting systems that include data pertaining to sudden unexpected infant death and sudden unexpected death in childhood.

“(2) UPDATE OF FORMS.—The Secretary shall assess whether updates are needed to the sudden unexpected infant death investigation reporting form used by the Centers for Disease Control and Prevention in order to improve the use of such form with other fatality case reporting systems supported by the Department of Health and Human Services, and shall make such updates as appropriate.

“(e) SUPPORT SERVICES.—

“(1) IN GENERAL.—The Secretary, acting through the Administrator, shall award grants to national organizations, State and local health departments, community-based organizations, and nonprofit organizations for the provision of support services to families who have had a child die of sudden unexpected infant death or sudden unexpected death in childhood.

“(2) APPLICATION.—To be eligible to receive a grant under subsection (1), an entity shall submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require.

“(3) USE OF FUNDS.—Amounts received under a grant awarded under paragraph (1) may be used—

“(A) to provide grief counseling, education, home visits, 24-hour hotlines, or information, resources, and referrals;

“(B) to ensure access to grief and bereavement services;

“(C) to build capacity in professionals working with families who experience a sudden death; or

“(D) to support peer-to-peer groups for families who have lost a child to sudden unexpected infant death or sudden unexpected death in childhood.

“(4) PREFERENCE.—In awarding grants under paragraph (1), the Secretary shall give preference to applicants that—

“(A) have a proven history of effective direct support services and interventions for sudden unexpected infant death and sudden unexplained death in childhood; and

“(B) demonstrate experience through collaborations and partnerships for delivering services described in paragraph (3).

“(f) DEFINITIONS.—In this section:

“(1) SUDDEN UNEXPECTED INFANT DEATH.—The term ‘sudden unexpected infant death’—

“(A) means the sudden death of an infant under 1 year of age that when first discovered did not have an obvious cause; and

“(B) includes—

“(i) such deaths that are explained; and

“(ii) such deaths that remain unexplained (which are known as sudden infant death syndrome).

“(2) SUDDEN UNEXPECTED DEATH IN CHILDHOOD.—The term ‘sudden unexpected death in childhood’—

“(A) means the sudden death of a child who is at least 1 year of age but not more than 17 years of age that, when first discovered, did not have an obvious cause; and

“(B) includes—

“(i) such deaths that are explained; and

“(ii) such deaths that remain unexplained (which are known as sudden unexplained death in childhood).

“(3) SUDDEN UNEXPLAINED DEATH IN CHILDHOOD.—The term ‘sudden unexplained death in childhood’ means a sudden unexpected death in childhood that remains unexplained after a thorough case investigation.

“(g) AUTHORIZATION OF APPROPRIATIONS.—For the purpose of carrying out this section, there is authorized to be appropriated \$33,000,000 for each of fiscal years 2021 through 2024.”.

SEC. 3. REPORT TO CONGRESS.

(a) IN GENERAL.—Not later than 2 years after the date of enactment of this Act, and biennially thereafter, the Secretary of Health and Human Services shall submit

to the Committee on Energy and Commerce of the House of Representatives and the Committee on Health, Education, Labor, and Pensions of the Senate a report that contains, with respect to the reporting period—

(1) information regarding the incidence and number of sudden unexpected infant deaths and sudden unexpected deaths in childhood (including the number of such infant and child deaths that remain unexplained after investigation), including, to the extent practicable—

(A) a summary of such information by racial and ethnic group, and by State;

(B) aggregate information obtained from death scene investigations and autopsies; and

(C) recommendations for reducing the incidence of sudden unexpected infant death and sudden unexpected death in childhood;

(2) an assessment of the extent to which various approaches of reducing and preventing sudden unexpected infant death and sudden unexpected death in childhood have been effective; and

(3) a description of the activities carried out under section 1121 of the Public Health Service Act (as added by section 2).

(b) DEFINITIONS.—In this section, the terms “sudden unexpected infant death” and “sudden unexpected death in childhood” have the meanings given such terms in section 1121 of the Public Health Service Act (as added by section 2).

I. PURPOSE AND SUMMARY

H.R. 2271, the “Scarlett’s Sunshine on Unexpected Death Act”, was introduced on April 10, 2019, by Representatives Gwen Moore (D-WI), Tom Cole (R-OK), Jaime Herrera Beutler (R-WA), Josh Gottheimer (D-NJ), Yvette Clarke (D-NY), Cathy McMorris Rodgers (R-WA), Debbie Wasserman Schultz (D-FL), Raul Grijalva (D-AZ), Ro Khanna (D-CA), Eleanor Holmes Norton (D-DC), Peter King (R-NY), Betty McCollum (D-MN), Matt Cartwright (D-PA), and Suzan DelBene (D-WA).

H.R. 2271 authorizes the Secretary of Health and Human Services (the Secretary) to continue to support the Sudden Unexplained Infant Death and Sudden Death in the Young Case Registry of the Centers for Disease Control and Prevention (CDC) and to issue grants for improving the completion of comprehensive death scene investigations for sudden unexplained infant death (SUID) and sudden unexplained death in children (SUDC), increasing the rate of comprehensive, standardized autopsies in cases of SUID and SUDC, and fostering the training of medical examiners, coroners, death scene investigators, law enforcement, and health professionals on standard death scene investigation protocols. H.R. 2271 also authorizes new grants through the Health Services and Resources Administration (HRSA) to develop and implement educational programs and outreach related to sleep-related SUID, and in addition to programs that deploy support services for families who have had a child die of SUID or SUDC.

II. BACKGROUND AND NEED FOR LEGISLATION

Sudden unexpected deaths, often described as sudden unexpected infant death (SUID) occurring to infants under the age of one year, and sudden unexpected death in childhood (SUIDC) occurring to children between the ages of one through 18 years old, refer to cases where an infant or child dies suddenly without an obvious cause when first discovered.

SUID is a broad term that includes deaths that occur due to sudden infant death syndrome (SIDS), accidental suffocation in a sleeping environment, metabolic diseases, cardiac arrhythmias, in-

fections, and other deaths from unknown causes in children under the age of one year.¹ SIDS is a diagnosis often made after a thorough investigation of an infant’s death in which no cause of death can be determined.² If there is some uncertainty about the cause of death—i.e., whether the death was caused by SIDS or another factor—a coroner or death examiner may note the cause of death as “unknown.”³ Although the causes of SIDS are not often known, research suggests infants who die from SIDS often have brain abnormalities or defects (within a nerve cell network that sends signals to other nerve cells), and are exposed to outside stressors during a critical period of development.⁴ There is currently no screening tests to determine whether infants have certain brain abnormalities that may make them vulnerable to SIDS.⁵

In 2017, there were 3,600 cases of SUID in the United States.⁶ Of these, approximately 1,400 were caused by SIDS.⁷ While SUID affects all demographic groups, significant racial disparities exist: American Indian, Alaska Native, and Black infants account for more than double the cases of SUID as White infants.⁸

Even less is known about SUDC. While data points to approximately 500 children ages 1–19 dying each year without a known cause despite an autopsy and investigation, there is very little data collection on SUDC and no code to report SUDC.⁹ While the CDC has a standardized form to collect investigation data on SUID, there is no standardization of data collection for investigations into SUDC.¹⁰

In response to these tragic data, H.R. 2271 would require CDC to revise the Sudden Unexplained Infant Death Investigation Reporting Form to include doll re-enactments and scene investigation information on sleep-related deaths for children under the age of five, and to align the form with the National Fatality Review Case Reporting System. The bill also authorizes CDC to make grants to improve the completion of comprehensive death scene investigations for SUID and SUDC, to increase the rate of comprehensive, standardized autopsies in cases of SUID and SUDC, and to train medical examiners, coroners, death scene investigators, law enforcement, and health professionals on standard death scene investigation protocols.

The bill also authorizes grants through the HRSA to develop and implement education and outreach initiatives related to sleep-related SUID, and programs to develop and deploy support services for families who have had a child die of SUID or SUDC.

¹National Institutes of Health, *Common SIDS and SUID Terms and Definitions* (2020) (<https://safetosleep.nichd.nih.gov/safesleepbasics/SIDS/Common>).

²National Institutes of Health, *What is SIDS?* (2020) (safetosleep.nichd.nih.gov/safesleepbasics/SIDS).

³*Id.*

⁴National Institutes of Health, *Research on Possible Causes of SIDS* (2020) (safetosleep.nichd.nih.gov/research/science/causes).

⁵National Institutes of Health, *What Causes SIDS?* (2020) (safetosleep.nichd.nih.gov/safesleepbasics/causes).

⁶Centers for Disease Control and Prevention, *Sudden Unexpected Infant Death and Sudden Infant Death Syndrome Data and Statistics* (2020) (www.cdc.gov/sids/data.htm).

⁷*Id.*

⁸*Id.*

⁹Laura Crandall and Orrin Devinsky, *Sudden Unexplained Death in Children*, *The Lancet Child and Adolescent Health*, Vol. 1, Issue 1, 8–9 (2017).

¹⁰*Id.*

III. COMMITTEE HEARINGS

For the purposes of section 103(i) of H. Res. 6 of the 116th Congress, the following hearing was used to develop or consider H.R. 2271:

The Subcommittee on Health held a legislative hearing on January 8, 2020, entitled “Legislation to Improve Americans’ Health Care Coverage and Outcomes” to consider H.R. 2271, the “Scarlett’s Sunshine on Sudden Unexpected Death Act”. The Subcommittee received testimony from the following witnesses:

Panel I:

- Lee Beers, M.D., President-Elect, American Academy of Pediatrics
- Kenneth Mendez, President and Chief Executive Officer, Asthma and Allergy Foundation of America
- Stephanie Zarecky, Mother of Scarlett Pauley, Ambassador Program and Public Relations Manager, SUDC Foundation

Panel II:

- Matthew Cooper, M.D., Director, Kidney and Pancreas Transplantation, Medical Director, Transplant QAPI, Medstar Georgetown Transplant Institute, Professor of Surgery, Georgetown University School of Medicine
- Kevin Koser, Patient Advocate
- Fred Riccardi, President Medicare Rights Center

IV. COMMITTEE CONSIDERATION

Representative Moore (D–WI) introduced on April 10, 2019, H.R. 2271, the “Scarlett’s Sunshine on Sudden Unexpected Death Act”, and the bill was referred to the Committee on Energy and Commerce. Subsequently, H.R. 2271 was referred to the Subcommittee on Health on April 11, 2019. A legislative hearing was held on the bill on January 8, 2020.

On March 11, 2020, the Subcommittee on Health met in open markup session, pursuant to notice, to consider H.R. 2271. During consideration of the bill, an amendment in the nature of a substitute (AINS) was offered by Ms. Blunt Rochester of Delaware. The Blunt Rochester AINS was agreed to by a voice vote. Subsequently, the Subcommittee on Health agreed by a voice vote to a motion by Ms. Eshoo, Chairwoman of the subcommittee, to forward favorably H.R. 2271, amended, to the full Committee on Energy and Commerce.

On July 15, 2020, the full Committee met in virtual open markup session, pursuant to notice, to consider a committee print of the bill H.R. 2271, as amended by the Subcommittee on Health on March 11, 2020. No amendments were offered to the committee print of H.R. 2271. Consideration of the bill completed, the full Committee agreed to a motion on final passage by Mr. Pallone, Chairman of the committee, to order H.R. 2271 reported favorably to the House, as amended, by a voice vote, a quorum being present.

V. COMMITTEE VOTES

Clause 3(b) of rule XIII of the Rules of the House of Representatives requires the Committee to list each record vote on the motion

to report legislation and amendments thereto. The Committee advises that there were no record votes taken on H.R. 2271, including the motion for final passage of the bill.

VI. OVERSIGHT FINDINGS

Pursuant to clause 3(c)(1) of rule XIII and clause 2(b)(1) of rule X of the Rules of the House of Representatives, the oversight findings and recommendations of the Committee are reflected in the descriptive portion of the report.

VII. NEW BUDGET AUTHORITY, ENTITLEMENT AUTHORITY, AND TAX EXPENDITURES

Pursuant to 3(c)(2) of rule XIII of the Rules of the House of Representatives, the Committee adopts as its own the estimate of new budget authority, entitlement authority, or tax expenditures or revenues contained in the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974.

VIII. CONGRESSIONAL BUDGET OFFICE ESTIMATE

U.S. CONGRESS,
CONGRESSIONAL BUDGET OFFICE,
Washington, DC, September 8, 2020.

Hon. FRANK PALLONE JR.,
*Chairman, Committee on Energy and Commerce,
House of Representatives, Washington, DC.*

DEAR MR. CHAIRMAN: The Congressional Budget Office has prepared the enclosed cost estimate for H.R. 2271, the Scarlett's Sunshine on Sudden Unexpected Death Act.

If you wish further details on this estimate, we will be pleased to provide them. The CBO staff contact is Lisa Ramirez-Branum.
Sincerely,

PHILLIP L. SWAGEL,
Director.

Enclosure.

H.R. 2271, Scarlett's Sunshine on Sudden Unexpected Death Act			
As ordered reported by the House Committee on Energy and Commerce on July 15, 2020			
By Fiscal Year, Millions of Dollars	2020	2020-2025	2020-2030
Direct Spending (Outlays)	0	0	0
Revenues	0	0	0
Increase or Decrease (-) in the Deficit	0	0	0
Spending Subject to Appropriation (Outlays)	0	121	not estimated
Statutory pay-as-you-go procedures apply?	No	Mandate Effects	
Increases on-budget deficits in any of the four consecutive 10-year periods beginning in 2031?	No	Contains intergovernmental mandate?	No
		Contains private-sector mandate?	No

H.R. 2271 would authorize the appropriation of \$33 million annually over the 2021–2024 period for the Secretary of Health and Human Services (HHS) to carry out activities that address sudden unexpected infant death (SUID). Those activities would include awarding grants to states and other organizations to develop best practices to reduce SUID, support systems to report fatalities, and provide services to families who have had a child die of SUID. In 2019, approximately \$2 million was allocated to support systems to report fatalities. The legislation also would require HHS to report biennially on the activities implemented related to SUID and to provide technical assistance to states receiving grants.

Assuming appropriation of the authorized amounts and based on historical spending for similar activities, CBO estimates that implementing the legislation would cost \$121 million over the 2020–2025 period. The costs of the legislation, detailed in Table 1, fall within budget function 550 (health).

TABLE 1.—ESTIMATED INCREASES IN SPENDING SUBJECT TO APPROPRIATION UNDER H.R. 2271

	By fiscal year, millions of dollars—						
	2020	2021	2022	2023	2024	2025	2020–2025
Estimated Authorization	0	33	33	33	33	0	132
Estimated Outlays	0	8	25	31	32	25	121

Components may not sum to totals due to rounding.

On November 27, 2019, CBO transmitted a cost estimate for S.1130, the Scarlett's Sunshine on Sudden Unexpected Death Act, as ordered reported by the Senate Committee on Health, Education, Labor and Pensions on November 27, 2019. The two pieces of legislation are similar. However, unlike S. 1130, H.R. 2271 would authorize HHS to provide grants to states to provide services to families who have had a child die of SUID. Thus, CBO's estimate of the cost of implementing H.R. 2271 is correspondingly higher.

The CBO staff contact for this estimate is Lisa Ramirez-Branum. The estimate was reviewed by Leo Lex, Deputy Director of Budget Analysis.

IX. FEDERAL MANDATES STATEMENT

The Committee adopts as its own the estimate of Federal mandates prepared by the Director of the Congressional Budget Office pursuant to section 423 of the Unfunded Mandates Reform Act.

X. STATEMENT OF GENERAL PERFORMANCE GOALS AND OBJECTIVES

Pursuant to clause 3(c)(4) of rule XIII, the general performance goal or objective of this legislation is to improve the health of infants and children and help better understand and enhance awareness about unexpected sudden death in early life.

XI. DUPLICATION OF FEDERAL PROGRAMS

Pursuant to clause 3(c)(5) of rule XIII, no provision of H.R. 2271 is known to be duplicative of another Federal program, including any program that was included in a report to Congress pursuant to section 21 of Public Law 111-139 or the most recent Catalog of Federal Domestic Assistance.

XII. COMMITTEE COST ESTIMATE

Pursuant to clause 3(d)(1) of rule XIII, the Committee adopts as its own the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974.

XIII. EARMARKS, LIMITED TAX BENEFITS, AND LIMITED TARIFF BENEFITS

Pursuant to clause 9(e), 9(f), and 9(g) of rule XXI, the Committee finds that H.R. 2271 contains no earmarks, limited tax benefits, or limited tariff benefits.

XIV. ADVISORY COMMITTEE STATEMENT

No advisory committee within the meaning of section 5(b) of the Federal Advisory Committee Act was created by this legislation.

XV. APPLICABILITY TO LEGISLATIVE BRANCH

The Committee finds that the legislation does not relate to the terms and conditions of employment or access to public services or accommodations within the meaning of section 102(b)(3) of the Congressional Accountability Act.

XVI. SECTION-BY-SECTION ANALYSIS OF THE LEGISLATION

Section 1. Short title

Section 1 designates that the short title may be cited as the “Scarlett’s Sunshine on Sudden Unexpected Death Act”.

Sec. 2. Addressing Sudden Unexpected Infant Death and Sudden Unexplained Death in Childhood

Section 2 amends the Public Health Service Act (42 U.S.C. 241 et seq.) to authorize the Secretary to develop, support, or maintain programs or activities to address SUID and SUDC. Such programs and activities may include continuing to support the Sudden Unexplained Infant Death and Sudden Death in the Young Case Registry of the CDC and other fatality case reporting systems that include data pertaining to SUID and SUDC. Such systems also include those supported by HRSA in order to increase the number of participating States and jurisdictions or improve the utility of such systems by making summary data available to the public in a timely manner on the internet website of the U.S. Department of Health and Human Services in a manner that protects personal privacy.

The Secretary is also authorized to award grants or cooperative agreements to States, Tribes, and Tribal organizations for five purposes. Grants may be used for the purpose of supporting and establishing fetal and infant mortality and child death review programs for SUID and SUDC at the local level. Second, grants may be used for the purpose of improving data collection related to SUID and SUID—such as improving the completion of death scene investigations and comprehensive autopsies, training medical examiners, coroners, death scene investigators, law enforcement personnel, emergency medical technicians, paramedics, emergency department personnel, and others who perform death scene investigations pertaining to SUID and SUDC. Third, grants may be used for identifying, developing, and implementing best practices to reduce or prevent SUID and SUDC, including practices to reduce sleep-related infant deaths. Grants may also be used for the purposes of increasing the voluntary inclusion of tissues or genetic materials from autopsies pertaining to SUID and SUDC. Finally grants may be used to disseminate information and materials to health care professionals and the public on SUID and SUDC risk factors, including sleep-related risk factors.

To be eligible to receive a grant or cooperative agreement under this section, entities are required to submit an application at such time, in such manner, and containing such information as the Secretary shall require, including information on how the grant recipient will ensure activities conducted under this section are coordinated with other Federally-funded programs to reduce infant mortality. The Secretary is required to provide technical assistance to entities receiving a grant or cooperative agreement under this section.

Section 2 also requires the Secretary to encourage the use of CDC-developed SUID and SUDC reporting forms to improve the quality of data submitted to the Sudden Unexpected Infant Death and Sudden Death in the Young Case Registry, and other fatality case reporting systems. Further, the Secretary shall assess whether updates are needed to such forms.

Finally, the Secretary is authorized to award grants to entities, such as national organizations, State and local health departments, community-based organizations, and nonprofit organizations for the provision of support services for grieving families and for capacity building for professionals working with grieving families. Such sup-

port services may include peer-to-peer counseling, education, home visits, 24-hour hotlines, informational materials and resources, referrals, and bereavement services. Preferences for such grants shall be given to entities that have a proven history of effective direct support services and interventions for SUID and SUDC.

This section defines Sudden Unexpected Infant Death to mean the sudden death of an infant under one year of age that when first discovered did not have an obvious cause and includes such deaths that are later explained and such deaths that remain unexplained. It also defines Sudden Unexpected Death in Childhood to mean a sudden unexpected death in childhood that remains unexplained after a thorough case investigation.

To carry out these activities, section 2 authorizes \$33,000,000 for each of the fiscal years 2021 through 2024.

Sec. 3. Report to Congress

Section 3 directs the Secretary to submit a report to the House Committee on Energy and Commerce and the Senate Committee on Health, Education, Labor, and Pensions no later than two years after the date of enactment of this Act. The report shall include information regarding the incidence and number of sudden unexpected infant deaths and sudden unexpected deaths in childhood, an assessment of the extent to which various approaches of reducing and preventing sudden unexpected infant death and sudden unexpected infant death in childhood have been effective, and a description of activities carried out under section 1121 of the Public Health Service Act.

XVII. CHANGES IN EXISTING LAW MADE BY THE BILL, AS REPORTED

In compliance with clause 3(e) of rule XIII of the Rules of the House of Representatives, changes in existing law made by the bill, as reported, are shown as follows (existing law proposed to be omitted is enclosed in black brackets, new matter is printed in italics, and existing law in which no change is proposed is shown in roman):

PUBLIC HEALTH SERVICE ACT

* * * * *

**TITLE XI—GENETIC DISEASES, HEMOPHILIA PROGRAMS,
AND SUDDEN INFANT DEATH SYNDROME**

* * * * *

PART B—[SUDDEN INFANT DEATH SYNDROME] *SUDDEN UNEXPECTED INFANT DEATH, SUDDEN INFANT DEATH SYNDROME, AND SUDDEN UNEXPECTED DEATH IN CHILDHOOD*

SEC. 1121. ADDRESSING SUDDEN UNEXPECTED INFANT DEATH AND SUDDEN UNEXPECTED DEATH IN CHILDHOOD.

(a) *IN GENERAL.*—*The Secretary may develop, support, or maintain programs or activities to address sudden unexpected infant death and sudden unexpected death in childhood, including by—*

(1) *continuing to support the Sudden Unexpected Infant Death and Sudden Death in the Young Case Registry of the*

Centers for Disease Control and Prevention and other fatality case reporting systems that include data pertaining to sudden unexpected infant death and sudden unexpected death in childhood, as appropriate, including such systems supported by the Health Resources and Services Administration, in order to—

- (A) increase the number of States and jurisdictions participating in such systems; or*
 - (B) improve the utility of such systems, which may include—*
 - (i) making summary data available to the public in a timely manner on the internet website of the Department of Health and Human Services, in a manner that, at a minimum, protects personal privacy to the extent required by applicable Federal and State law; and*
 - (ii) making the data submitted to such systems available to researchers, in a manner that, at a minimum, protects personal privacy to the extent required by applicable Federal and State law; and*
- (2) awarding grants or cooperative agreements to States, Indian Tribes, and Tribal organizations for purposes of—*
- (A) supporting fetal and infant mortality and child death review programs for sudden unexpected infant death and sudden unexpected death in childhood, including by establishing such programs at the local level;*
 - (B) improving data collection related to sudden unexpected infant death and sudden unexpected death in childhood, including by—*
 - (i) improving the completion of death scene investigations and comprehensive autopsies that include a review of clinical history and circumstances of death with appropriate ancillary testing; and*
 - (ii) training medical examiners, coroners, death scene investigators, law enforcement personnel, emergency medical technicians, paramedics, emergency department personnel, and others who perform death scene investigations with respect to the deaths of infants and children, as appropriate;*
 - (C) identifying, developing, and implementing best practices to reduce or prevent sudden unexpected infant death and sudden unexpected death in childhood, including practices to reduce sleep-related infant deaths;*
 - (D) increasing the voluntary inclusion, in fatality case reporting systems established for the purpose of conducting research on sudden unexpected infant death and sudden unexpected death in childhood, of samples of tissues or genetic materials from autopsies that have been collected pursuant to Federal or State law; or*
 - (E) disseminating information and materials to health care professionals and the public on risk factors that contribute to sudden unexpected infant death and sudden unexpected death in childhood, which may include information on risk factors that contribute to sleep-related sudden unexpected infant death or sudden unexpected death in childhood.*

(b) *APPLICATION.*—To be eligible to receive a grant or cooperative agreement under subsection (a)(2), a State, Indian Tribe, or Tribal organization shall submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require, including information on how such State will ensure activities conducted under this section are coordinated with other federally-funded programs to reduce infant mortality, as appropriate.

(c) *TECHNICAL ASSISTANCE.*—The Secretary shall provide technical assistance to States, Tribes, and Tribal organizations receiving a grant or cooperative agreement under subsection (a)(2) for purposes of carrying out activities funded through the grant or cooperative agreement.

(d) *REPORTING FORMS.*—

(1) *IN GENERAL.*—The Secretary shall, as appropriate, encourage the use of sudden unexpected infant death and sudden unexpected death in childhood reporting forms developed in collaboration with the Centers for Disease Control and Prevention to improve the quality of data submitted to the Sudden Unexpected Infant Death and Sudden Death in the Young Case Registry, and other fatality case reporting systems that include data pertaining to sudden unexpected infant death and sudden unexpected death in childhood.

(2) *UPDATE OF FORMS.*—The Secretary shall assess whether updates are needed to the sudden unexpected infant death investigation reporting form used by the Centers for Disease Control and Prevention in order to improve the use of such form with other fatality case reporting systems supported by the Department of Health and Human Services, and shall make such updates as appropriate.

(e) *SUPPORT SERVICES.*—

(1) *IN GENERAL.*—The Secretary, acting through the Administrator, shall award grants to national organizations, State and local health departments, community-based organizations, and nonprofit organizations for the provision of support services to families who have had a child die of sudden unexpected infant death or sudden unexpected death in childhood.

(2) *APPLICATION.*—To be eligible to receive a grant under subsection (1), an entity shall submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require.

(3) *USE OF FUNDS.*—Amounts received under a grant awarded under paragraph (1) may be used—

(A) to provide grief counseling, education, home visits, 24-hour hotlines, or information, resources, and referrals;

(B) to ensure access to grief and bereavement services;

(C) to build capacity in professionals working with families who experience a sudden death; or

(D) to support peer-to-peer groups for families who have lost a child to sudden unexpected infant death or sudden unexpected death in childhood.

(4) *PREFERENCE.*—In awarding grants under paragraph (1), the Secretary shall give preference to applicants that—

(A) have a proven history of effective direct support services and interventions for sudden unexpected infant death and sudden unexplained death in childhood; and

(B) demonstrate experience through collaborations and partnerships for delivering services described in paragraph (3).

(f) DEFINITIONS.—In this section:

(1) SUDDEN UNEXPECTED INFANT DEATH.—The term “sudden unexpected infant death”—

(A) means the sudden death of an infant under 1 year of age that when first discovered did not have an obvious cause; and

(B) includes—

(i) such deaths that are explained; and

(ii) such deaths that remain unexplained (which are known as sudden infant death syndrome).

(2) SUDDEN UNEXPECTED DEATH IN CHILDHOOD.—The term “sudden unexpected death in childhood”—

(A) means the sudden death of a child who is at least 1 year of age but not more than 17 years of age that, when first discovered, did not have an obvious cause; and

(B) includes—

(i) such deaths that are explained; and

(ii) such deaths that remain unexplained (which are known as sudden unexplained death in childhood).

(3) SUDDEN UNEXPLAINED DEATH IN CHILDHOOD.—The term “sudden unexplained death in childhood” means a sudden unexpected death in childhood that remains unexplained after a thorough case investigation.

(g) AUTHORIZATION OF APPROPRIATIONS.—For the purpose of carrying out this section, there is authorized to be appropriated \$33,000,000 for each of fiscal years 2021 through 2024.

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