

116TH CONGRESS  
1ST SESSION

# 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.

---

## IN THE HOUSE OF REPRESENTATIVES

APRIL 10, 2019

Ms. MOORE (for herself, Mr. COLE, Ms. HERRERA BEUTLER, Mr. GOTTHEIMER, Ms. CLARKE of New York, Mrs. RODGERS of Washington, Ms. WASSERMAN SCHULTZ, Mr. GRIJALVA, Mr. KHANNA, Ms. NORTON, Mr. KING of New York, Ms. MCCOLLUM, Mr. CARTWRIGHT, and Ms. DELBENE) introduced the following bill; which was referred to the Committee on Energy and Commerce

---

## A BILL

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.

1       *Be it enacted by the Senate and House of Representa-  
2 tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

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

## 1 SEC. 2. AMENDMENT TO THE PUBLIC HEALTH SERVICE

## 2 ACT.

3 Title III of the Public Health Service Act (42 U.S.C.

4 241 et seq.) is amended by adding at the end the fol-

5 lowing:

6 **PART W—SUDDEN UNEXPECTED INFANT DEATH**7 **AND SUDDEN UNEXPECTED DEATH IN**8 **CHILDHOOD**9 **SEC. 399OO. DEFINITIONS.**

10 “In this part:

11 “(1) ADMINISTRATOR.—The term ‘Administrator’ means the Administrator of the Health Resources and Services Administration.

14 “(2) DEATH SCENE INVESTIGATOR.—The term ‘death scene investigator’ means an individual certified or trained as a death scene investigator by an accredited professional certification board.

18 “(3) DIRECTOR.—The term ‘Director’ means the Director of the Centers for Disease Control and Prevention.

21 “(4) STATE.—The term ‘State’ has the meaning given to such term in section 2, except that such term includes Indian tribes and tribal organizations (as such terms are defined in section 4 of the Indian Self-Determination and Education Assistance Act).

1                   “(5) SUDDEN UNEXPECTED INFANT DEATH;  
2 SUID.—The terms ‘sudden unexpected infant death’  
3 and ‘SUID’ mean the sudden death of an infant  
4 under 1 year of age that when first discovered did  
5 not have an obvious cause. Such terms include those  
6 deaths that are later determined to be from ex-  
7 plained as well as unexplained causes.

“(6) SUDDEN UNEXPECTED DEATH IN CHILDHOOD; SUDC.—The terms ‘sudden unexpected death in childhood’ and ‘SUDC’ mean the sudden death of a child who is 1 year of age or older that, when first discovered, did not have an obvious cause. Such terms include those deaths that are later determined to be from an explained cause, and those deaths that remain unexplained after a thorough case investigation that includes a review of the clinical history and circumstances of death and performance of a comprehensive, standardized autopsy with appropriate ancillary testing (which are known as ‘sudden unexplained death in childhood’).

21 "SEC. 399OO-1. DEATH SCENE INVESTIGATION AND AU-  
22 TOPSY.

23        "(a) INVESTIGATIONS.—

24               “(1) REPORTING.—The Secretary, acting  
25 through the Director, in consultation with experts

1       that include board-certified forensic pathologists,  
2       medical examiners, coroners, pediatric pathologists,  
3       pediatric cardiologists, pediatric neuropathologists  
4       and geneticists, and other individuals and groups as  
5       the Director determines appropriate, shall revise the  
6       Sudden Unexplained Infant Death Investigation Re-  
7       porting Form of the Centers for Disease Control and  
8       Prevention to include doll re-enactments and scene  
9       investigation information on sleep-related deaths of  
10      children younger than 5, and work to align such  
11      form with the National Fatality Review Case Re-  
12      porting System.

13           “(2) GRANTS.—The Secretary, acting through  
14       the Director, shall award grants to States to enable  
15       such States to improve the completion of comprehen-  
16       sive death scene investigations, and reviews of such  
17       investigations, for sudden unexpected infant death  
18       and sudden unexpected death in childhood.

19           “(3) APPLICATION.—To be eligible to receive a  
20       grant under paragraph (2), a State shall submit to  
21       the Secretary an application at such time, in such  
22       manner, and containing such information as the Sec-  
23       retary may require.

24           “(4) USE OF FUNDS.—

1                 “(A) IN GENERAL.—A State shall use  
2 amounts received under a grant under para-  
3 graph (2) to improve the completion of com-  
4 prehensive death scene investigations for sud-  
5 den unexpected infant death and sudden unex-  
6 pected death in childhood, including through  
7 the awarding of subgrants to local jurisdictions  
8 (which may include subgrants to medical exam-  
9 iners, coroners, and other local entities respon-  
10 sible for conducting autopsies) to be used to im-  
11 plement standard death scene investigation pro-  
12 tocols for sudden unexpected infant death and  
13 sudden unexpected death in childhood and con-  
14 duct comprehensive, standardized autopsies.

15                 “(B) PROTOCOLS.—A standard death  
16 scene protocol implemented under subparagraph  
17 (A) shall include the obtaining of information  
18 on—

19                         “(i) current and past medical history  
20 of the infant or child and, as relevant, the  
21 infant’s or child’s family;

22                         “(ii) the circumstances surrounding  
23 the death, including any suspicious cir-  
24 cumstances, whether there were any acci-

1                    dental or environmental factors associated  
2                    with the death; and

3                    “(iii) in the case of a sleep-related  
4                    death, the sleep position and sleep environ-  
5                    ment of the infant or child.

6         “(b) AUTOPSIES.—

7                    “(1) IN GENERAL.—The Secretary, acting  
8                    through the Director, shall award grants to States  
9                    and local governmental entities to enable such States  
10                  and entities to increase the rate at which com-  
11                  prehensive, standardized autopsies are performed for  
12                  sudden unexpected infant death and sudden unex-  
13                  pected death in childhood.

14                  “(2) INFORMED CONSENT.—Grants awarded  
15                  under this subsection may be used for studies and  
16                  demonstration projects to increase the rate of con-  
17                  sent among families of deceased children for the in-  
18                  clusion of genetic or tissue samples collected during  
19                  autopsy in registries established for the purposes of  
20                  conducting research into SUID and SUDC.

21                  “(3) APPLICATION.—To be eligible to receive a  
22                  grant under paragraph (1), an eligible entity de-  
23                  scribed in such paragraph shall submit to the Sec-  
24                  retary an application that includes—

1               “(A) a description of the methods to be  
2               studied or tested to increase the rate of consent  
3               among families of deceased children for the in-  
4               clusion of genetic or tissue samples collected  
5               during autopsy;

6               “(B) information about the governmental  
7               and nongovernmental entities with whom the el-  
8               igible entity will partner; and

9               “(C) any additional information as the  
10              Secretary may require.

11              “(4) COMPREHENSIVE AUTOPSY.—For purposes  
12              of this subsection, a comprehensive, standardized au-  
13              topsy includes, as appropriate, a full external and in-  
14              ternal examination, including microscopic examina-  
15              tion, of all major organs and tissues including the  
16              brain, complete radiographs, vitreous fluid analysis,  
17              photo documentation, metabolic testing, toxicology  
18              screening, and, when indicated, selected genetic and  
19              microbiology analyses of the infant or child involved.

20              “(c) GENETIC ANALYSIS.—The Director, in consulta-  
21              tion with medical examiners, coroners, forensic patholo-  
22              gists, geneticists, researchers, public health officials, and  
23              other individuals and groups as the Director determines  
24              appropriate, shall develop recommendations for a standard  
25              protocol for use in determining when to utilize genetic

1 analysis, and standard protocols for the collection and  
2 storage of specimens suitable for genetic analysis.

3       “(d) AUTHORIZATION OF APPROPRIATIONS.—To  
4 carry out this section, there is authorized to be appro-  
5 priated \$8,000,000 for each of fiscal years 2019 through  
6 2023.

7 **“SEC. 399OO–2. TRAINING.**

8       “(a) GRANTS.—The Secretary, acting through the  
9 Director, shall award grants to eligible entities for the pro-  
10 vision of training on death scene investigation specific for  
11 SUID and SUDC.

12       “(b) ELIGIBLE ENTITIES.—To be eligible to receive  
13 a grant under subsection (a), an entity shall—

14           “(1) be—

15              “(A) a State or local government entity; or

16              “(B) a nonprofit private entity;

17           “(2) submit to the Secretary an application at  
18 such time, in such manner, and containing such in-  
19 formation as the Secretary may require; and

20           “(3) make publishing training materials devel-  
21 oped using a grant awarded under subsection (a)  
22 available on an internet website and at no charge to  
23 attendees of training under subsection (c)(1).

24       “(c) USE OF FUNDS.—An eligible entity shall use  
25 amounts received under a grant under this section to—

1           “(1) provide training to medical examiners,  
2 coroners, death scene investigators, law enforcement  
3 personnel, justices of the peace, emergency medical  
4 technicians, paramedics, or emergency department  
5 personnel concerning death scene investigations for  
6 SUID and SUDC, including the use of standard  
7 death scene investigation protocols that include in-  
8 formation on—

9           “(A) current and past medical history of  
10 the infant or child and, as relevant, the infant’s  
11 or child’s family;

12           “(B) the circumstances surrounding the  
13 death, including any suspicious circumstances;

14           “(C) whether there were any accidental or  
15 environmental factors associated with the death;  
16 and

17           “(D) in the case of a sleep-related death,  
18 the sleep position and sleep environment of the  
19 infant or child;

20           “(2) provide training directly to individuals who  
21 are responsible for conducting and reviewing death  
22 scene investigations for sudden unexpected infant  
23 death and sudden unexpected death in childhood;

24           “(3) provide training to multidisciplinary teams,  
25 including teams that have a medical examiner or

1       coroner, death scene investigator, law enforcement  
2       representative, and an emergency medical technician  
3       or paramedic;

4           “(4) in the case of national and State-based  
5       grantees that are comprised of medical examiners,  
6       coroners, death scene investigators, law enforcement  
7       personnel, or emergency medical technicians and  
8       paramedics, integrate training under the grant on  
9       death scene investigation of SUID and SUDC into  
10      professional accreditation and training programs; or

11           “(5) in the case of State and local government  
12      entity grantees, obtain equipment, including scene  
13      investigation kits, to aid in the completion of stand-  
14      ard death scene investigation.

15           “(d) AUTHORIZATION OF APPROPRIATIONS.—To  
16      carry out this section, there is authorized to be appro-  
17      priated \$2,000,000 for each of fiscal years 2019 through  
18      2023.

19      **“SEC. 399OO–3. INFANT AND CHILD DEATH REVIEW.**

20           “(a) PREVENTION.—

21           “(1) CORE CAPACITY GRANTS.—The Secretary,  
22      acting through the Administrator and in consulta-  
23      tion with the Associate Commissioner of the Chil-  
24      dren’s Bureau of the Administration for Children  
25      and Families, shall award grants to States to build

1 and strengthen State capacity, and enable States to  
2 support local governments' capacity, so as to review  
3 100 percent of all infant and child deaths, and to  
4 develop and implement prevention strategies, as ap-  
5 propriate.

6       “(2) PLANNING GRANTS.—The Secretary, act-  
7 ing through the Administrator, shall award planning  
8 grants to States in which the only infant and child  
9 death review programs are statewide, for the devel-  
10 opment of local infant and child death review pro-  
11 grams and prevention strategies.

12       “(3) APPLICATION.—To be eligible to receive a  
13 grant under paragraph (1) or (2), a State shall sub-  
14 mit to the Secretary an application at such time, in  
15 such manner, and containing such information as  
16 the Secretary may require.

17       “(4) TECHNICAL ASSISTANCE.—The Secretary,  
18 acting through the Administrator, shall provide tech-  
19 nical assistance to assist States—

20           “(A) in developing the capacity for com-  
21 prehensive infant and child death review pro-  
22 grams, including the development of best prac-  
23 tices for the implementation of such programs;  
24 and

1                 “(B) in maintaining the National Fatality  
2                 Review Case Reporting System.

3                 “(b) AUTHORIZATION OF APPROPRIATIONS.—To  
4 carry out this section, there is authorized to be appro-  
5 priated \$15,000,000 for each of fiscal years 2019 through  
6 2023.

7 **“SEC. 399OO-4. ENHANCING THE NATIONAL FATALITY RE-**  
8 **VIEW CASE REPORTING SYSTEM.**

9                 “(a) IN GENERAL.—The Secretary, acting through  
10 the Director and in consultation with the National Fatal-  
11 ity Review Case Reporting System, national health organi-  
12 zations, and professional societies with experience and ex-  
13 pertise relating to reducing SUID and SUDC, shall main-  
14 tain current efforts of the National Fatality Review Case  
15 Reporting System so as to provide population-based data  
16 on unexpected deaths occurring for infants or children  
17 under age 18, in order to facilitate the understanding of  
18 the root causes, rates, trends, and geographic variations  
19 of SUID and SUDC.

20                 “(b) COMPILED AND AVAILABILITY OF DATA.—  
21 The Secretary shall—

22                 “(1) compile the data submitted under this sec-  
23 tion;

1           “(2) make summary data available to the public  
2       in a timely manner on an appropriate internet  
3       website in a format that is useful to the public; and

4           “(3) make data submitted under this section  
5       available, in a manner that protects the privacy of  
6       individuals involved, to individuals or entities con-  
7       ducting research into the causes of, or prevention  
8       methods for, SUID and SUDC.

9           “(c) AUTHORIZATION OF APPROPRIATIONS.—To  
10      carry out this section, there is authorized to be appro-  
11      priated \$1,000,000 for each of fiscal years 2019 through  
12      2023.

13   **“SEC. 399OO–5. GRANTS TO SUPPORT INFANT SAFE SLEEP.**

14           “(a) IN GENERAL.—The Secretary, acting through  
15      the Administrator, shall award grants to national organi-  
16      zations, community-based organizations, municipal public  
17      safety departments, and nonprofit organizations for the  
18      provision of evidence-based approaches for educational  
19      programs, and outreach activities focused on decreasing  
20      the risk factors that contribute to sleep-related SUID.

21           “(b) APPLICATION.—To be eligible to receive a grant  
22      under subsection (a), an entity shall submit to the Sec-  
23      retary an application at such time, in such manner, and  
24      containing such information as the Secretary may require.

1       “(c) USE OF FUNDS.—Amounts received under a  
2 grant awarded under subsection (a) may be used to—

3           “(1) provide outreach and education services di-  
4 rectly to parents and families, which—

5              “(A) may include home visits, 24-hour hot-  
6 lines, internet-based educational materials, mo-  
7 bile health technologies, and social marketing  
8 campaigns;

9              “(B) shall apply current safe sleep guide-  
10 lines published by a professional pediatric orga-  
11 nization; and

12           “(C) may provide safe sleep-related prod-  
13 ucts to families at no cost or at reduced cost  
14 that have published, peer-reviewed evidence to  
15 support safer sleep environments for infants  
16 through age one; or

17           “(2) build capacity in professionals working  
18 with families to support safe sleep.

19        “(d) SAFE-SLEEP PRODUCTS.—Any product related  
20 to safe sleep for an infant that is provided under sub-  
21 section (c)(1)(C) shall—

22           “(1) be in compliance with current safe sleep  
23 guidelines published by a professional pediatric orga-  
24 nization;

1           “(2) be intended for use by the infant through  
2       age one; and

3           “(3) be covered by, and be in compliance with,  
4       a regulation or mandatory standard promulgated by  
5       the Consumer Product Safety Commission.

6           “(e) PREFERENCE.—In awarding grants under sub-  
7       section (a), the Secretary shall give preference to appli-  
8       cants that have a proven history of developing or deliv-  
9       ering interventions for infants and families to support safe  
10      sleep, include plans to report evidence of program out-  
11      comes, and can demonstrate experience through collabora-  
12      tions and partnerships for delivering services throughout  
13      a State or region.

14           “(f) SET-ASIDE.—Not more than 5 percent of the  
15      amount of funds appropriated to carry out this section  
16      may be used to conduct research into the behavioral risks  
17      that lead to unsafe sleep practices and ways to mitigate  
18      those risks.

19           “(g) AUTHORIZATION OF APPROPRIATIONS.—To  
20      carry out this section, there is authorized to be appro-  
21      priated \$5,000,000 for fiscal year 2019 and \$7,000,000  
22      for each of fiscal years 2020 through 2023.

23 **“SEC. 399OO–6. GRANTS FOR SUPPORT SERVICES.**

24           “(a) IN GENERAL.—The Secretary, acting through  
25      the Administrator, shall award grants to national organi-

1 zations, State and local health departments, community-  
2 based organizations, and nonprofit organizations for the  
3 provision of support services to families who have had a  
4 child die of sudden unexpected infant death or sudden un-  
5 explained death in childhood.

6       “(b) APPLICATION.—To be eligible to receive a grant  
7 under subsection (a), an entity shall submit to the Sec-  
8 retary an application at such time, in such manner, and  
9 containing such information as the Secretary may require.

10       “(c) USE OF FUNDS.—Amounts received under a  
11 grant awarded under subsection (a) may be used—

12           “(1) to provide grief counseling, education,  
13 home visits, 24-hour hotlines, or information, re-  
14 sources, and referrals;

15           “(2) to ensure access to grief and bereavement  
16 services;

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

19           “(4) to support groups for families who have  
20 lost a child to sudden unexpected infant death or  
21 sudden unexplained death in childhood.

22       “(d) PREFERENCE.—In awarding grants under sub-  
23 section (a), the Secretary shall give preference to appli-  
24 cants that—

1           “(1) have a proven history of effective direct  
2       support services and interventions for sudden unex-  
3       pected infant death and sudden unexplained death in  
4       childhood; and

5           “(2) demonstrate experience through collabora-  
6       tions and partnerships for delivering services de-  
7       scribed in subsection (c).

8       **“(e) AUTHORIZATION OF APPROPRIATIONS.—**There  
9       is authorized to be appropriated to carry out this section  
10      \$1,000,000 for each of fiscal years 2019 through 2023.”.

11      **SEC. 3. SENSE OF CONGRESS.**

12       It is the sense of Congress that additional research  
13       is needed to improve the understanding of the epidemi-  
14       ology of sudden unexpected infant and childhood deaths  
15       that remain unexplained following a comprehensive, stand-  
16       ardized autopsy and appropriate ancillary testing.

17      **SEC. 4. REPORT TO CONGRESS.**

18       Not later than 1 year after the date of enactment  
19       of this Act, and biennially thereafter, the Secretary of  
20       Health and Human Services, acting through the Director  
21       of the Centers for Disease Control and Prevention and in  
22       consultation with the Director of the National Institutes  
23       of Health and the Administrator of the Health Resources  
24       and Services Administration, shall submit to the Com-  
25       mittee on Health, Education, Labor, and Pensions of the

1 Senate and the Committee on Energy and Commerce of  
2 the House of Representatives a report that contains, with  
3 respect to the preceding reporting period—

4                 (1) information regarding the absolute number  
5                 and incidence of sudden unexpected infant death,  
6                 the absolute number and incidence of sudden unex-  
7                 pected death in childhood, information about the  
8                 number of such infant and child deaths that remain  
9                 unexplained, information about such conditions by  
10                racial and ethnic groups, information about such  
11                conditions by State, aggregate information obtained  
12                from death scene investigations and autopsies, and  
13                recommendations for reducing the incidence of sud-  
14                den unexpected infant death and sudden unexpected  
15                death in childhood;

16                 (2) an assessment of the extent to which var-  
17                 ious approaches of preventing sudden unexpected in-  
18                 fant death have been effective;

19                 (3) a description of the activities carried out  
20                 under part W of title III of the Public Health Serv-  
21                 ice Act (as added by section 2); and

22                 (4) any recommendations of the Secretary re-  
23                 garding such part W.

