

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. 3990O. DEFINITIONS.**

10 “In this part:

11 “(1) ADMINISTRATOR.—The term ‘Adminis-
12 trator’ means the Administrator of the Health Re-
13 sources and Services Administration.

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

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

21 “(4) STATE.—The term ‘State’ has the mean-
22 ing given to such term in section 2, except that such
23 term includes Indian tribes and tribal organizations
24 (as such terms are defined in section 4 of the Indian
25 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.

8 “(6) SUDDEN UNEXPECTED DEATH IN CHILD-
9 HOOD; SUDC.—The terms ‘sudden unexpected death
10 in childhood’ and ‘SUDC’ mean the sudden death of
11 a child who is 1 year of age or older that, when first
12 discovered, did not have an obvious cause. Such
13 terms include those deaths that are later determined
14 to be from an explained cause, and those deaths that
15 remain unexplained after a thorough case investiga-
16 tion that includes a review of the clinical history and
17 circumstances of death and performance of a com-
18 prehensive, standardized autopsy with appropriate
19 ancillary testing (which are known as ‘sudden unex-
20 plained death in childhood’).

21 **“SEC. 39900-1. 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. 39900–2. 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. 39900-3. 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. 39900–4. 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) COMPILATION 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. 39900-5. 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. 39900-6. 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.

○