

116TH CONGRESS
1ST SESSION

S. 1130

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 SENATE OF THE UNITED STATES

APRIL 10, 2019

Mr. CASEY (for himself, Mr. ISAKSON, Mr. BROWN, and Mr. JONES) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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.—The term ‘sudden unexpected death in
 10 childhood’ means the sudden death of a child who is
 11 1 year of age or older that, when first discovered,
 12 did not have an obvious cause. Such term includes
 13 those deaths that are later determined to be from an
 14 explained cause, and those deaths that remain unex-
 15 plained after a thorough case investigation that in-
 16 cludes a review of the clinical history and cir-
 17 cumstances 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 sudden unexpected infant
21 deaths and sudden unexpected death in childhood.

22 “(3) APPLICATION.—To be eligible to receive a
23 grant under paragraph (1), an eligible entity de-
24 scribed in such paragraph shall submit to the Sec-
25 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 sudden unexpected infant death and sudden unexpected
12 death in childhood.

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

15 “(1) be—

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

17 “(B) a nonprofit private entity;

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

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

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

3 “(1) provide training to medical examiners,
4 coroners, death scene investigators, law enforcement
5 personnel, justices of the peace, emergency medical
6 technicians, paramedics, or emergency department
7 personnel concerning death scene investigations for
8 sudden unexpected infant death and sudden unex-
9 pected death in childhood, including the use of
10 standard death scene investigation protocols that in-
11 clude information on—

12 “(A) current and past medical history of
13 the infant or child and, as relevant, the infant’s
14 or child’s family;

15 “(B) the circumstances surrounding the
16 death, including any suspicious circumstances;

17 “(C) whether there were any accidental or
18 environmental factors associated with the death;
19 and

20 “(D) in the case of a sleep-related death,
21 the sleep position and sleep environment of the
22 infant or child;

23 “(2) provide training directly to individuals who
24 are responsible for conducting and reviewing death

1 scene investigations for sudden unexpected infant
2 death and sudden unexpected death in childhood;

3 “(3) provide training to multidisciplinary teams,
4 including teams that have a medical examiner or
5 coroner, death scene investigator, law enforcement
6 representative, and an emergency medical technician
7 or paramedic;

8 “(4) in the case of national and State-based
9 grantees that are comprised of medical examiners,
10 coroners, death scene investigators, law enforcement
11 personnel, or emergency medical technicians and
12 paramedics, integrate training under the grant on
13 death scene investigation of sudden unexpected in-
14 fant death and sudden unexpected death in child-
15 hood into professional accreditation and training
16 programs; or

17 “(5) in the case of State and local government
18 entity grantees, obtain equipment, including scene
19 investigation kits, to aid in the completion of stand-
20 ard death scene investigation.

21 “(d) AUTHORIZATION OF APPROPRIATIONS.—To
22 carry out this section, there is authorized to be appro-
23 priated \$2,000,000 for each of fiscal years 2019 through
24 2023.

1 **“SEC. 39900-3. INFANT AND CHILD DEATH REVIEW.**

2 “(a) PREVENTION.—

3 “(1) CORE CAPACITY GRANTS.—The Secretary,
4 acting through the Administrator and in consulta-
5 tion with the Associate Commissioner of the Chil-
6 dren’s Bureau of the Administration for Children
7 and Families, shall award grants to States to build
8 and strengthen State capacity, and enable States to
9 support local governments’ capacity, so as to review
10 100 percent of all infant and child deaths, and to
11 develop and implement prevention strategies, as ap-
12 propriate.

13 “(2) PLANNING GRANTS.—The Secretary, act-
14 ing through the Administrator, shall award planning
15 grants to States in which the only infant and child
16 death review programs are statewide, for the devel-
17 opment of local infant and child death review pro-
18 grams and prevention strategies.

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

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

1 “(A) in developing the capacity for com-
2 prehensive infant and child death review pro-
3 grams, including the development of best prac-
4 tices for the implementation of such programs;
5 and

6 “(B) in maintaining the National Fatality
7 Review Case Reporting System.

8 “(b) AUTHORIZATION OF APPROPRIATIONS.—To
9 carry out this section, there is authorized to be appro-
10 priated \$15,000,000 for each of fiscal years 2019 through
11 2023.

12 **“SEC. 39900-4. ENHANCING THE NATIONAL FATALITY RE-
13 VIEW CASE REPORTING SYSTEM.**

14 “(a) IN GENERAL.—The Secretary, acting through
15 the Director and in consultation with the National Fatal-
16 ity Review Case Reporting System, national health organi-
17 zations, and professional societies with experience and ex-
18 pertise relating to reducing sudden unexpected infant
19 death and sudden unexpected death in childhood, shall
20 maintain current efforts of the National Fatality Review
21 Case Reporting System so as to provide population-based
22 data on unexpected deaths occurring for infants or chil-
23 dren under age 18, in order to facilitate the understanding
24 of the root causes, rates, trends, and geographic variations

1 of sudden unexpected infant death and sudden unexpected
2 death in childhood.

3 “(b) COMPILATION AND AVAILABILITY OF DATA.—

4 The Secretary shall—

5 “(1) compile the data submitted under this sec-
6 tion;

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

10 “(3) make data submitted under this section
11 available, in a manner that protects the privacy of
12 individuals involved, to individuals or entities con-
13 ducting research into the causes of, or prevention
14 methods for, sudden unexpected infant death and
15 sudden unexpected death in childhood.

16 “(c) AUTHORIZATION OF APPROPRIATIONS.—To
17 carry out this section, there is authorized to be appro-
18 priated \$1,000,000 for each of fiscal years 2019 through
19 2023.

20 **“SEC. 39900-5. GRANTS TO SUPPORT INFANT SAFE SLEEP.**

21 “(a) IN GENERAL.—The Secretary, acting through
22 the Administrator, shall award grants to national organi-
23 zations, community-based organizations, municipal public
24 safety departments, and nonprofit organizations for the
25 provision of evidence-based approaches for educational

1 programs, and outreach activities focused on decreasing
2 the risk factors that contribute to sleep-related SUID.

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

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

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

11 “(A) may include home visits, 24-hour hot-
12 lines, internet-based educational materials, mo-
13 bile health technologies, and social marketing
14 campaigns;

15 “(B) shall apply current safe sleep guide-
16 lines published by a professional pediatric orga-
17 nization; and

18 “(C) may provide safe sleep-related prod-
19 ucts to families at no cost or at reduced cost
20 that have published, peer-reviewed evidence to
21 support safer sleep environments for infants
22 through age one; or

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

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

4 “(1) be in compliance with current safe sleep
5 guidelines published by a professional pediatric orga-
6 nization;

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

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

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

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

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

5 **SEC. 3. SENSE OF CONGRESS.**

6 It is the sense of Congress that additional research
7 is needed to improve the understanding of the epidemi-
8 ology of sudden unexpected infant and childhood deaths
9 that remain unexplained following a comprehensive, stand-
10 ardized autopsy and appropriate ancillary testing.

11 **SEC. 4. REPORT TO CONGRESS.**

12 Not later than 1 year after the date of enactment
13 of this Act, and biennially thereafter, the Secretary of
14 Health and Human Services, acting through the Director
15 of the Centers for Disease Control and Prevention and in
16 consultation with the Director of the National Institutes
17 of Health and the Administrator of the Health Resources
18 and Services Administration, shall submit to the Com-
19 mittee on Health, Education, Labor, and Pensions of the
20 Senate and the Committee on Energy and Commerce of
21 the House of Representatives a report that contains, with
22 respect to the preceding reporting period—

23 (1) information regarding the absolute number
24 and incidence of sudden unexpected infant death,
25 the absolute number and incidence of sudden unex-

1 pected death in childhood, information about the
2 number of such infant and child deaths that remain
3 unexplained, information about such conditions by
4 racial and ethnic groups, information about such
5 conditions by State, aggregate information obtained
6 from death scene investigations and autopsies, and
7 recommendations for reducing the incidence of sud-
8 den unexpected infant death and sudden unexpected
9 death in childhood;

10 (2) an assessment of the extent to which var-
11 ious approaches of preventing sudden unexpected in-
12 fant death and sudden unexpected death in child-
13 hood have been effective;

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

17 (4) any recommendations of the Secretary re-
18 garding such part W.

○