

115TH CONGRESS
2D SESSION

S. 3521

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

SEPTEMBER 27, 2018

Mr. CASEY (for himself, Mr. ISAKSON, and Mr. BROWN) 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 UNEXPLAINED DEATH IN**
 8 **CHILDHOOD**

9 **“SEC. 39900. 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 UNEXPLAINED DEATH IN CHILD-
 9 HOOD; SUDC.—The terms ‘sudden unexplained death
 10 in childhood’ and ‘SUDC’ mean the sudden death of
 11 a child who is 1 year of age or older, which remains
 12 unexplained after a thorough case investigation that
 13 includes a review of the clinical history and cir-
 14 cumstances of death and performance of a complete
 15 autopsy with appropriate ancillary testing.

16 **“SEC. 39900-1. DEATH SCENE INVESTIGATION AND AU-**
 17 **TOPSY.**

18 “(a) INVESTIGATIONS.—

19 “(1) REPORTING.—The Secretary, acting
 20 through the Director, in consultation with board-cer-
 21 tified forensic pathologists, medical examiners, coro-
 22 ners, pediatric pathologists, pediatric cardiologists,
 23 pediatric neuropathologists and geneticists, and
 24 other individuals and groups as the Director deter-
 25 mines necessary, shall revise the Sudden Unex-

1 plained Infant Death Investigation Reporting Form
2 of the Centers for Disease Control and Prevention
3 and the Child Death Review Case Reporting System
4 to include doll re-enactments and scene investigation
5 information on deaths of children younger than 5.

6 “(2) GRANTS.—The Secretary, acting through
7 the Director, shall award grants to States to enable
8 such States to improve the completion of comprehen-
9 sive death scene investigations, and reviews of such
10 investigations, for sudden unexpected infant death
11 and sudden unexplained death in childhood.

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

17 “(4) USE OF FUNDS.—

18 “(A) IN GENERAL.—A State shall use
19 amounts received under a grant under para-
20 graph (1) to improve the completion of com-
21 prehensive death scene investigations for sud-
22 den unexpected infant death and sudden unex-
23 plained death in childhood, including through
24 the awarding of subgrants to local jurisdictions
25 to be used to implement standard death scene

1 investigation protocols for sudden unexpected
2 infant death and sudden unexplained death in
3 childhood and conduct comprehensive, stand-
4 ardized autopsies.

5 “(B) PROTOCOLS.—A standard death
6 scene protocol implemented under subparagraph
7 (A) shall include the obtaining of information
8 on current and past medical history of the in-
9 fant or child, the circumstances surrounding
10 the death, including any suspicious cir-
11 cumstances, whether there were any accidental
12 or environmental factors associated with the
13 death, and in the case of a sleep-related death,
14 the sleep position and sleep environment.

15 “(b) AUTOPSIES.—

16 “(1) IN GENERAL.—The Secretary, acting
17 through the Director, shall award grants to States
18 and local governmental entities to enable such States
19 and entities to increase the rate at which com-
20 prehensive, standardized autopsies are performed for
21 sudden unexpected infant death and sudden unex-
22 plained death in childhood.

23 “(2) INFORMED CONSENT.—Grants awarded
24 under this subsection may be used for studies and
25 demonstration projects to increase the rate of con-

1 sent among families of deceased children for the in-
2 clusion of genetic or tissue samples collected during
3 autopsy in registries established for the purposes of
4 conducting research into SUID and SUDC.

5 “(3) APPLICATION.—To be eligible to receive a
6 grant under paragraph (1), an eligible entity de-
7 scribed in such paragraph shall submit to the Sec-
8 retary an application at such time, in such manner,
9 and containing such information as the Secretary
10 may require.

11 “(4) COMPREHENSIVE AUTOPSY.—For purposes
12 of this subsection, a comprehensive autopsy, which
13 may include minimally invasive techniques, shall in-
14 clude a full external and internal examination, in-
15 cluding microscopic examination, of all major organs
16 and tissues including the brain, complete radio-
17 graphs, vitreous fluid analysis, photo documentation,
18 metabolic testing, toxicology screening, and, when
19 indicated, selected genetic and microbiology analyses
20 of the infant or child involved.

21 “(c) STUDY ON GENETIC ANALYSIS.—The Director,
22 in consultation with medical examiners, coroners, forensic
23 pathologists, geneticists, researchers, public health offi-
24 cials, and other individuals and groups as the Director de-
25 termines necessary, shall commission a study to determine

1 the benefits and appropriateness of genetic analysis for in-
 2 fant and early childhood deaths that remain unexplained
 3 after a complete death scene investigation and comprehen-
 4 sive, standardized autopsy. Such study shall include rec-
 5 ommendations on developing a standard protocol for use
 6 in determining when to utilize genetic analysis, and stand-
 7 ard protocols for the collection and storage of specimens
 8 suitable for genetic analysis.

9 “(d) AUTHORIZATION OF APPROPRIATIONS.—To
 10 carry out this section, there is authorized to be appro-
 11 priated \$8,000,000 for each of fiscal years 2018 through
 12 2022.

13 **“SEC. 39900-2. TRAINING.**

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

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

20 “(1) be—

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

22 “(B) a nonprofit private entity;

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

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

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

7 “(1) provide training to medical examiners,
8 coroners, death scene investigators, law enforcement
9 personnel, justices of the peace, emergency medical
10 technicians, paramedics, or emergency department
11 personnel concerning death scene investigations for
12 SUID and SUDC, including the use of standard
13 death scene investigation protocols that include in-
14 formation on the current and past medical history of
15 the infant or child, the circumstances surrounding
16 the death including any suspicious circumstances,
17 the sleep position and sleep environment of the in-
18 fant or child, and whether there were any accidental
19 or environmental factors associated with the death;

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 unexplained 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 2018 through
 18 2022.

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 so as to review 100
2 percent of all infant and child deaths, and to develop
3 and implement prevention strategies, as appropriate.

4 “(2) PLANNING GRANTS.—The Secretary, act-
5 ing through the Administrator, shall award planning
6 grants to States that have no existing infant or child
7 death review program or States in which the only in-
8 fant and child death review programs are State-
9 based, for the development of local infant and child
10 death review programs and prevention strategies.

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

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

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

24 “(B) in maintaining the National Infant
25 and Child Death Case Reporting System.

1 “(b) AUTHORIZATION OF APPROPRIATIONS.—To
 2 carry out this section, there is authorized to be appro-
 3 priated \$15,000,000 for each of fiscal years 2018 through
 4 2022.

5 **“SEC. 39900–4. ENHANCING THE NATIONAL INFANT AND**
 6 **CHILD DEATH CASE REPORTING SYSTEM.**

7 “(a) IN GENERAL.—The Secretary, acting through
 8 the Director and in consultation with the National Infant
 9 and Child Death Case Reporting System, national health
 10 organizations, and professional societies with experience
 11 and expertise relating to reducing SUID and SUDC, shall
 12 maintain current efforts of the National Infant and Child
 13 Death Case Reporting System so as to provide population-
 14 based data on deaths occurring for children under age 5,
 15 in order to facilitate the understanding of the root causes,
 16 rates, trends, and geographic variations of SUID and
 17 SUDC with respect to such age group.

18 “(b) COMPILATION AND AVAILABILITY OF DATA.—
 19 The Secretary shall compile the data submitted under this
 20 section and make such data available to the public in a
 21 timely manner on an appropriate internet website in a for-
 22 mat that is useful to the public and to other entities.

23 “(c) AUTHORIZATION OF APPROPRIATIONS.—To
 24 carry out this section, there is authorized to be appro-

1 priated \$1,000,000 for each of fiscal years 2018 through
2 2022.

3 **“SEC. 39900–5. GRANTS TO SUPPORT INFANT SAFE SLEEP.**

4 “(a) IN GENERAL.—The Secretary, acting through
5 the Administrator, shall award grants to national organi-
6 zations, community-based organizations, municipal public
7 safety departments, and nonprofit organizations for the
8 provision of evidence-based approaches for educational
9 programs, and outreach activities focused on decreasing
10 the risk factors that contribute to SUID.

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

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

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

19 “(A) may include home visits, 24-hour hot-
20 lines, internet-based educational materials, mo-
21 bile health technologies, and social marketing
22 campaigns;

23 “(B) shall apply current safe sleep guide-
24 lines published by a professional pediatric orga-
25 nization; and

1 “(C) may provide safe sleep-related prod-
2 ucts to families at no cost or at reduced cost
3 that have published, peer-reviewed evidence to
4 support safer sleep environments for infants
5 through age one; or

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

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

11 “(1) be a full-sized crib, a non-full-sized crib, or
12 a play yard;

13 “(2) provide a flat surface;

14 “(3) not include a supplemental mattress or
15 soft bedding; and

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

19 “(e) PREFERENCE.—In awarding grants under sub-
20 section (a), the Secretary shall give preference to appli-
21 cants that have a proven history of developing or deliv-
22 ering interventions for infants and families to support safe
23 sleep, include plans to report evidence of program out-
24 comes, and can demonstrate experience through collabora-

1 tions and partnerships for delivering services throughout
2 a State or region.

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

8 “(g) AUTHORIZATION OF APPROPRIATIONS.—To
9 carry out this section, there is authorized to be appro-
10 priated \$5,000,000 for fiscal year 2018 and \$7,000,000
11 for each of fiscal years 2019 through 2022.”.

12 **SEC. 3. SENSE OF CONGRESS.**

13 It is the sense of Congress that additional research
14 is needed to improve the understanding of the epidemi-
15 ology of sudden unexplained death in childhood.

16 **SEC. 4. REPORT TO CONGRESS.**

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

1 the House of Representatives a report that contains, with
2 respect to the preceding 1-year reporting period—

3 (1) information regarding the absolute number
4 and incidence of both sudden unexpected infant
5 death and sudden unexplained death in childhood,
6 information about such conditions by racial and eth-
7 nic groups, information about such conditions by
8 State, aggregate information obtained from death
9 scene investigations and autopsies, and recommenda-
10 tions for reducing the incidence of sudden unex-
11 pected infant death and sudden unexplained death in
12 childhood;

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

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

19 (4) any recommendations of the Secretary re-
20 garding such part W.

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