

Union Calendar No.

116TH CONGRESS
2^D SESSION

H. R. 2271

[Report No. 116-]

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

JULY --, 2020

Reported with an amendment, committed to the Committee of the Whole House on the State of the Union, and ordered to be printed

[Strike out all after the enacting clause and insert the part printed in *italic*]

[For text of introduced bill, see copy of bill as introduced on April 10, 2019]

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 on*
5 *Sudden Unexpected Death Act”.*

6 **SEC. 2. ADDRESSING SUDDEN UNEXPECTED INFANT DEATH**
7 **AND SUDDEN UNEXPECTED DEATH IN CHILD-**
8 **HOOD.**

9 *Part B of title XI of the Public Health Service Act*
10 *(42 U.S.C. 241 et seq.) is amended—*

11 *(1) in the part heading, by striking “SUDDEN*
12 *INFANT DEATH SYNDROME” and inserting “SUDDEN*
13 *UNEXPECTED INFANT DEATH, SUDDEN INFANT*
14 *DEATH SYNDROME, AND SUDDEN UNEXPECTED*
15 *DEATH IN CHILDHOOD”;* and

16 *(2) by inserting before section 1122 the following:*

17 **“SEC. 1121. ADDRESSING SUDDEN UNEXPECTED INFANT**
18 **DEATH AND SUDDEN UNEXPECTED DEATH IN**
19 **CHILDHOOD.**

20 *“(a) IN GENERAL.—The Secretary may develop, sup-*
21 *port, or maintain programs or activities to address sudden*
22 *unexpected infant death and sudden unexpected death in*
23 *childhood, including by—*

24 *“(1) continuing to support the Sudden Unex-*
25 *pected Infant Death and Sudden Death in the Young*

1 *Case Registry of the Centers for Disease Control and*
2 *Prevention and other fatality case reporting systems*
3 *that include data pertaining to sudden unexpected in-*
4 *fant death and sudden unexpected death in childhood,*
5 *as appropriate, including such systems supported by*
6 *the Health Resources and Services Administration, in*
7 *order to—*

8 *“(A) increase the number of States and ju-*
9 *risdictions participating in such systems; or*

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

12 *“(i) making summary data available*
13 *to the public in a timely manner on the*
14 *internet website of the Department of*
15 *Health and Human Services, in a manner*
16 *that, at a minimum, protects personal pri-*
17 *vacancy to the extent required by applicable*
18 *Federal and State law; and*

19 *“(ii) making the data submitted to*
20 *such systems available to researchers, in a*
21 *manner that, at a minimum, protects per-*
22 *sonal privacy to the extent required by ap-*
23 *plicable Federal and State law; and*

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

4 “(A) *supporting fetal and infant mortality*
5 *and child death review programs for sudden un-*
6 *expected infant death and sudden unexpected*
7 *death in childhood, including by establishing*
8 *such programs at the local level;*

9 “(B) *improving data collection related to*
10 *sudden unexpected infant death and sudden un-*
11 *expected death in childhood, including by—*

12 “(i) *improving the completion of death*
13 *scene investigations and comprehensive au-*
14 *topsies that include a review of clinical his-*
15 *tory and circumstances of death with ap-*
16 *propriate ancillary testing; and*

17 “(ii) *training medical examiners, coro-*
18 *ners, death scene investigators, law enforce-*
19 *ment personnel, emergency medical techni-*
20 *cians, paramedics, emergency department*
21 *personnel, and others who perform death*
22 *scene investigations with respect to the*
23 *deaths of infants and children, as appro-*
24 *priate;*

1 “(C) *identifying, developing, and imple-*
2 *menting best practices to reduce or prevent sud-*
3 *den unexpected infant death and sudden unex-*
4 *pected death in childhood, including practices to*
5 *reduce sleep-related infant deaths;*

6 “(D) *increasing the voluntary inclusion, in*
7 *fatality case reporting systems established for the*
8 *purpose of conducting research on sudden unex-*
9 *pected infant death and sudden unexpected death*
10 *in childhood, of samples of tissues or genetic ma-*
11 *terials from autopsies that have been collected*
12 *pursuant to Federal or State law; or*

13 “(E) *disseminating information and mate-*
14 *rials to health care professionals and the public*
15 *on risk factors that contribute to sudden unex-*
16 *pected infant death and sudden unexpected death*
17 *in childhood, which may include information on*
18 *risk factors that contribute to sleep-related sud-*
19 *den unexpected infant death or sudden unex-*
20 *pected death in childhood.*

21 “(b) *APPLICATION.—To be eligible to receive a grant*
22 *or cooperative agreement under subsection (a)(2), a State,*
23 *Indian Tribe, or Tribal organization shall submit to the*
24 *Secretary an application at such time, in such manner, and*
25 *containing such information as the Secretary may require,*

1 *including information on how such State will ensure activi-*
2 *ties conducted under this section are coordinated with other*
3 *federally-funded programs to reduce infant mortality, as*
4 *appropriate.*

5 “(c) *TECHNICAL ASSISTANCE.—The Secretary shall*
6 *provide technical assistance to States, Tribes, and Tribal*
7 *organizations receiving a grant or cooperative agreement*
8 *under subsection (a)(2) for purposes of carrying out activi-*
9 *ties funded through the grant or cooperative agreement.*

10 “(d) *REPORTING FORMS.—*

11 “(1) *IN GENERAL.—The Secretary shall, as ap-*
12 *propriate, encourage the use of sudden unexpected in-*
13 *fant death and sudden unexpected death in childhood*
14 *reporting forms developed in collaboration with the*
15 *Centers for Disease Control and Prevention to im-*
16 *prove the quality of data submitted to the Sudden*
17 *Unexpected Infant Death and Sudden Death in the*
18 *Young Case Registry, and other fatality case report-*
19 *ing systems that include data pertaining to sudden*
20 *unexpected infant death and sudden unexpected death*
21 *in childhood.*

22 “(2) *UPDATE OF FORMS.—The Secretary shall*
23 *assess whether updates are needed to the sudden unex-*
24 *pected infant death investigation reporting form used*
25 *by the Centers for Disease Control and Prevention in*

1 *order to improve the use of such form with other fa-*
2 *tality case reporting systems supported by the De-*
3 *partment of Health and Human Services, and shall*
4 *make such updates as appropriate.*

5 *“(e) SUPPORT SERVICES.—*

6 *“(1) IN GENERAL.—The Secretary, acting*
7 *through the Administrator, shall award grants to na-*
8 *tional organizations, State and local health depart-*
9 *ments, community-based organizations, and nonprofit*
10 *organizations for the provision of support services to*
11 *families who have had a child die of sudden unex-*
12 *pected infant death or sudden unexpected death in*
13 *childhood.*

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

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

21 *“(A) to provide grief counseling, education,*
22 *home visits, 24-hour hotlines, or information, re-*
23 *sources, and referrals;*

24 *“(B) to ensure access to grief and bereave-*
25 *ment services;*

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

4 “(D) to support peer-to-peer groups for fam-
5 ilies who have lost a child to sudden unexpected
6 infant death or sudden unexpected death in
7 childhood.

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

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

15 “(B) demonstrate experience through col-
16 laborations and partnerships for delivering serv-
17 ices described in paragraph (3).

18 “(f) DEFINITIONS.—In this section:

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

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

24 “(B) includes—

1 “(i) such deaths that are explained;

2 and

3 “(ii) such deaths that remain unex-
4 plained (which are known as sudden infant
5 death syndrome).

6 “(2) *SUDDEN UNEXPECTED DEATH IN CHILD-*
7 *HOOD.—The term ‘sudden unexpected death in child-*
8 *hood’—*

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

13 “(B) includes—

14 “(i) such deaths that are explained;

15 and

16 “(ii) such deaths that remain unex-
17 plained (which are known as sudden unex-
18 plained death in childhood).

19 “(3) *SUDDEN UNEXPLAINED DEATH IN CHILD-*
20 *HOOD.—The term ‘sudden unexplained death in*
21 *childhood’ means a sudden unexpected death in child-*
22 *hood that remains unexplained after a thorough case*
23 *investigation.*

24 “(g) *AUTHORIZATION OF APPROPRIATIONS.—For the*
25 *purpose of carrying out this section, there is authorized to*

1 *be appropriated \$33,000,000 for each of fiscal years 2021*
2 *through 2024.”.*

3 **SEC. 3. REPORT TO CONGRESS.**

4 *(a) IN GENERAL.—Not later than 2 years after the*
5 *date of enactment of this Act, and biennially thereafter, the*
6 *Secretary of Health and Human Services shall submit to*
7 *the Committee on Energy and Commerce of the House of*
8 *Representatives and the Committee on Health, Education,*
9 *Labor, and Pensions of the Senate a report that contains,*
10 *with respect to the reporting period—*

11 *(1) information regarding the incidence and*
12 *number of sudden unexpected infant deaths and sud-*
13 *den unexpected deaths in childhood (including the*
14 *number of such infant and child deaths that remain*
15 *unexplained after investigation), including, to the ex-*
16 *tent practicable—*

17 *(A) a summary of such information by ra-*
18 *cial and ethnic group, and by State;*

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

21 *(C) recommendations for reducing the inci-*
22 *dence of sudden unexpected infant death and*
23 *sudden unexpected death in childhood;*

24 *(2) an assessment of the extent to which various*
25 *approaches of reducing and preventing sudden unex-*

1 *pected infant death and sudden unexpected death in*
2 *childhood have been effective; and*

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

6 *(b) DEFINITIONS.—In this section, the terms “sudden*
7 *unexpected infant death” and “sudden unexpected death in*
8 *childhood” have the meanings given such terms in section*
9 *1121 of the Public Health Service Act (as added by section*
10 *2).*