

## Committee Print

[SHOWING THE TEXT OF H.R. 2271, AS FAVORABLY FORWARDED BY THE  
ENERGY AND COMMERCE SUBCOMMITTEE ON HEALTH ON MARCH 11, 2020]

116TH CONGRESS  
2D 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.

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### IN THE HOUSE OF REPRESENTATIVES

M\_\_\_\_ introduced the following bill; which was referred to the  
Committee on \_\_\_\_\_

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## 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. ADDRESSING SUDDEN UNEXPECTED INFANT DEATH**  
2 **AND SUDDEN UNEXPECTED DEATH IN CHILD-**  
3 **HOOD.**

4 Part B of title XI of the Public Health Service Act  
5 (42 U.S.C. 241 et seq.) is amended—

6 (1) in the part heading, by striking “**SUDDEN**  
7 **INFANT DEATH SYNDROME**” and inserting “**SUD-**  
8 **DEN UNEXPECTED INFANT DEATH, SUDDEN IN-**  
9 **FANT DEATH SYNDROME, AND SUDDEN UNEX-**  
10 **PECTED DEATH IN CHILDHOOD**”; and

11 (2) by inserting before section 1122 the fol-  
12 lowing:

13 **“SEC. 1121. ADDRESSING SUDDEN UNEXPECTED INFANT**  
14 **DEATH AND SUDDEN UNEXPECTED DEATH IN**  
15 **CHILDHOOD.**

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

20 “(1) continuing to support the Sudden Unex-  
21 pected Infant Death and Sudden Death in the  
22 Young Case Registry of the Centers for Disease  
23 Control and Prevention and other fatality case re-  
24 porting systems that include data pertaining to sud-  
25 den unexpected infant death and sudden unexpected  
26 death in childhood, as appropriate, including such

1 systems supported by the Health Resources and  
2 Services Administration, in order to—

3 “(A) increase the number of States and ju-  
4 risdictions participating in such systems; or

5 “(B) improve the utility of such systems,  
6 which may include—

7 “(i) making summary data available  
8 to the public in a timely manner on the  
9 internet website of the Department of  
10 Health and Human Services, in a manner  
11 that, at a minimum, protects personal pri-  
12 vacy to the extent required by applicable  
13 Federal and State law; and

14 “(ii) making the data submitted to  
15 such systems available to researchers, in a  
16 manner that, at a minimum, protects per-  
17 sonal privacy to the extent required by ap-  
18 plicable Federal and State law; and

19 “(2) awarding grants or cooperative agreements  
20 to States, Indian Tribes, and Tribal organizations  
21 for purposes of—

22 “(A) supporting fetal and infant mortality  
23 and child death review programs for sudden un-  
24 expected infant death and sudden unexpected

1 death in childhood, including by establishing  
2 such programs at the local level;

3 “(B) improving data collection related to  
4 sudden unexpected infant death and sudden un-  
5 expected death in childhood, including by—

6 “(i) improving the completion of death  
7 scene investigations and comprehensive au-  
8 topsies that include a review of clinical his-  
9 tory and circumstances of death with ap-  
10 propriate ancillary testing; and

11 “(ii) training medical examiners, coro-  
12 ners, death scene investigators, law en-  
13 forcement personnel, emergency medical  
14 technicians, paramedics, emergency depart-  
15 ment personnel, and others who perform  
16 death scene investigations with respect to  
17 the deaths of infants and children, as ap-  
18 propriate;

19 “(C) identifying, developing, and imple-  
20 menting best practices to reduce or prevent  
21 sudden unexpected infant death and sudden un-  
22 expected death in childhood, including practices  
23 to reduce sleep-related infant deaths;

24 “(D) increasing the voluntary inclusion, in  
25 fatality case reporting systems established for

1 the purpose of conducting research on sudden  
2 unexpected infant death and sudden unexpected  
3 death in childhood, of samples of tissues or ge-  
4 netic materials from autopsies that have been  
5 collected pursuant to Federal or State law; or  
6 “(E) disseminating information and mate-  
7 rials to health care professionals and the public  
8 on risk factors that contribute to sudden unex-  
9 pected infant death and sudden unexpected  
10 death in childhood, which may include informa-  
11 tion on risk factors that contribute to sleep-re-  
12 lated sudden unexpected infant death or sudden  
13 unexpected death in childhood.

14 “(b) APPLICATION.—To be eligible to receive a grant  
15 or cooperative agreement under subsection (a)(2), a State,  
16 Indian Tribe, or Tribal organization shall submit to the  
17 Secretary an application at such time, in such manner,  
18 and containing such information as the Secretary may re-  
19 quire, including information on how such State will ensure  
20 activities conducted under this section are coordinated  
21 with other federally-funded programs to reduce infant  
22 mortality, as appropriate.

23 “(c) TECHNICAL ASSISTANCE.—The Secretary shall  
24 provide technical assistance to States, Tribes, and Tribal  
25 organizations receiving a grant or cooperative agreement

1 under subsection (a)(2) for purposes of carrying out ac-  
2 tivities funded through the grant or cooperative agree-  
3 ment.

4 “(d) REPORTING FORMS.—

5 “(1) IN GENERAL.—The Secretary shall, as ap-  
6 propriate, encourage the use of sudden unexpected  
7 infant death and sudden unexpected death in child-  
8 hood reporting forms developed in collaboration with  
9 the Centers for Disease Control and Prevention to  
10 improve the quality of data submitted to the Sudden  
11 Unexpected Infant Death and Sudden Death in the  
12 Young Case Registry, and other fatality case report-  
13 ing systems that include data pertaining to sudden  
14 unexpected infant death and sudden unexpected  
15 death in childhood.

16 “(2) UPDATE OF FORMS.—The Secretary shall  
17 assess whether updates are needed to the sudden un-  
18 expected infant death investigation reporting form  
19 used by the Centers for Disease Control and Preven-  
20 tion in order to improve the use of such form with  
21 other fatality case reporting systems supported by  
22 the Department of Health and Human Services, and  
23 shall make such updates as appropriate.

24 “(e) SUPPORT SERVICES.—

1           “(1) IN GENERAL.—The Secretary, acting  
2 through the Administrator, shall award grants to  
3 national organizations, State and local health de-  
4 partments, community-based organizations, and non-  
5 profit organizations for the provision of support  
6 services to families who have had a child die of sud-  
7 den unexpected infant death or sudden unexpected  
8 death in childhood.

9           “(2) APPLICATION.—To be eligible to receive a  
10 grant under subsection (1), an entity shall submit to  
11 the Secretary an application at such time, in such  
12 manner, and containing such information as the Sec-  
13 retary may require.

14           “(3) USE OF FUNDS.—Amounts received under  
15 a grant awarded under paragraph (1) may be  
16 used—

17                   “(A) to provide grief counseling, education,  
18 home visits, 24-hour hotlines, or information,  
19 resources, and referrals;

20                   “(B) to ensure access to grief and bereave-  
21 ment services;

22                   “(C) to build capacity in professionals  
23 working with families who experience a sudden  
24 death; or

1           “(D) to support peer-to-peer groups for  
2 families who have lost a child to sudden unex-  
3 pected infant death or sudden unexpected death  
4 in childhood.

5           “(4) PREFERENCE.—In awarding grants under  
6 paragraph (1), the Secretary shall give preference to  
7 applicants that—

8           “(A) have a proven history of effective di-  
9 rect support services and interventions for sud-  
10 den unexpected infant death and sudden unex-  
11 plained death in childhood; and

12           “(B) demonstrate experience through col-  
13 laborations and partnerships for delivering serv-  
14 ices described in paragraph (3).

15           “(f) DEFINITIONS.—In this section:

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

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

21           “(B) includes—

22           “(i) such deaths that are explained;  
23 and



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

4                   “(2) SUDDEN UNEXPECTED DEATH IN CHILD-  
5                   HOOD.—The term ‘sudden unexpected death in  
6                   childhood’—

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

11                  “(B) includes—

12                   “(i) such deaths that are explained;  
13                   and

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

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

22                  “(g) AUTHORIZATION OF APPROPRIATIONS.—For the  
23                  purpose of carrying out this section, there is authorized  
24                  to be appropriated \$33,000,000 for each of fiscal years  
25                  2021 through 2024.”.

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

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

9 (1) information regarding the incidence and  
10 number of sudden unexpected infant deaths and  
11 sudden unexpected deaths in childhood (including  
12 the number of such infant and child deaths that re-  
13 main unexplained after investigation), including, to  
14 the extent practicable—

15 (A) a summary of such information by ra-  
16 cial and ethnic group, and by State;

17 (B) aggregate information obtained from  
18 death scene investigations and autopsies; and

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

22 (2) an assessment of the extent to which var-  
23 ious approaches of reducing and preventing sudden  
24 unexpected infant death and sudden unexpected  
25 death in childhood have been effective; and

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

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