

116TH CONGRESS
2^D SESSION

S. 1130

AN ACT

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,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Scarlett’s Sunshine
3 on Sudden Unexpected Death Act”.

4 **SEC. 2. AMENDMENT TO THE PUBLIC HEALTH SERVICE
5 ACT.**

6 Part B of title XI of the Public Health Service Act
7 (42 U.S.C. 241 et seq.) is amended—

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

13 (2) by inserting before section 1122 the fol-
14 lowing:

15 **“SEC. 1121. ADDRESSING SUDDEN UNEXPECTED INFANT**
16 **DEATH AND SUDDEN UNEXPECTED DEATH IN**
17 **CHILDHOOD.**

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

22 “(1) continuing to support the Sudden Unex-
23 pected Infant Death and Sudden Death in the
24 Young Case Registry of the Centers for Disease
25 Control and Prevention and other fatality case re-
26 porting systems that include data pertaining to sud-

1 den unexpected infant death and sudden unexpected
2 death in childhood, as appropriate, including such
3 systems supported by the Health Resources and
4 Services Administration, in order to—

5 “(A) increase the number of States and ju-
6 risdictions participating in such registries or
7 systems; and

8 “(B) improve the utility of such registries
9 or systems, which may include—

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

17 “(ii) making the data submitted to
18 such registries or systems available to re-
19 searchers, in a manner that, at a min-
20 imum, protects personal privacy to the ex-
21 tent required by applicable Federal and
22 State law; and

23 “(2) awarding grants or cooperative agreements
24 to States, Indian Tribes, and Tribal organizations
25 for purposes of—

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

6 “(B) improving data collection related to
7 sudden unexpected infant death and sudden un-
8 expected death in childhood, including by—

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

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

22 “(C) identifying, developing, and imple-
23 menting best practices to reduce or prevent
24 sudden unexpected infant death and sudden un-

1 expected death in childhood, including practices
2 to reduce sleep-related infant deaths;

3 “(D) increasing the voluntary inclusion, in
4 registries established for the purpose of con-
5 ducting research on sudden unexpected infant
6 death and sudden unexpected death in child-
7 hood, of samples of tissues or genetic materials
8 from autopsies that have been collected pursu-
9 ant to Federal or State law and for which the
10 parent or guardian has provided informed con-
11 sent for inclusion in such registries; or

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

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

1 activities conducted under this section are coordinated
2 with other federally-funded programs to reduce infant
3 mortality, as appropriate.

4 “(c) TECHNICAL ASSISTANCE.—The Secretary shall
5 provide technical assistance to States, Tribes, and Tribal
6 organizations receiving a grant or cooperative agreement
7 under subsection (a)(2) for purposes of carrying out the
8 program in accordance with this section.

9 “(d) REPORTING FORMS.—

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

21 “(2) UPDATE OF FORMS.—The Secretary shall
22 assess whether updates are needed to the sudden un-
23 expected infant death investigation reporting form
24 used by the Centers for Disease Control and Preven-
25 tion in order to improve the use of such form with

1 other fatality case reporting systems supported by
2 the Department of Health and Human Services, and
3 shall make such updates as appropriate.

4 “(e) DEFINITIONS.—In this section:

5 “(1) SUDDEN INFANT DEATH SYNDROME.—The
6 term ‘sudden infant death syndrome’ means a sud-
7 den unexpected infant death that remains unex-
8 plained after a thorough case investigation.

9 “(2) SUDDEN UNEXPECTED INFANT DEATH.—
10 The term ‘sudden unexpected infant death’ means
11 the sudden death of an infant under 1 year of age
12 that when first discovered did not have an obvious
13 cause. Such term includes such deaths that are ex-
14 plained, as well as deaths that remain unexplained
15 (which are known as sudden infant death syndrome).

16 “(3) SUDDEN UNEXPECTED DEATH IN CHILD-
17 HOOD.—The term ‘sudden unexpected death in
18 childhood’ means the sudden death of a child who is
19 at least 1 year of age but not more than 17 years
20 of age that, when first discovered, did not have an
21 obvious cause. Such term includes such deaths that
22 are explained, as well as deaths that remain unex-
23 plained (which are known as sudden unexplained
24 death in childhood).

1 “(4) SUDDEN UNEXPLAINED DEATH IN CHILD-
2 HOOD.—The term ‘sudden unexplained death in
3 childhood’ means a sudden unexpected death in
4 childhood that remains unexplained after a thorough
5 case investigation.

6 “(f) AUTHORIZATION OF APPROPRIATIONS.—For the
7 purpose of carrying out this section, there is authorized
8 to be appropriated \$12,000,000 for each of fiscal years
9 2021 through 2025.”.

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

11 (a) IN GENERAL.—Not later than 2 years after the
12 date of enactment of this Act and biennially thereafter,
13 the Secretary of Health and Human Services shall submit
14 to the Committee on Health, Education, Labor, and Pen-
15 sions of the Senate and the Committee on Energy and
16 Commerce of the House of Representatives a report that
17 contains, with respect to the reporting period—

18 (1) information regarding the incidence and
19 number of sudden unexpected infant death and sud-
20 den unexpected death in childhood (including the
21 number of such infant and child deaths that remain
22 unexplained after investigation), including, to the ex-
23 tent practicable—

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

1 (B) aggregate information obtained from
2 death scene investigations and autopsies; and

3 (C) recommendations for reducing the inci-
4 dence of sudden unexpected infant death and
5 sudden unexpected death in childhood;

6 (2) an assessment of the extent to which var-
7 ious approaches of reducing and preventing sudden
8 unexpected infant death and sudden unexpected
9 death in childhood have been effective; and

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

13 (b) DEFINITIONS.—In this section, the terms “sud-
14 den unexpected infant death” and “sudden unexpected
15 death in childhood” have the meanings given such terms
16 in section 1121 of the Public Health Service Act (as added
17 by section 2).

Passed the Senate May 20, 2020.

Attest:

Secretary.

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