

116TH CONGRESS
2D SESSION

H. R. 2271

IN THE SENATE OF THE UNITED STATES

SEPTEMBER 22, 2020

Received; read twice and referred to the Committee on Health, Education,
Labor, and Pensions

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. ADDRESSING SUDDEN UNEXPECTED INFANT DEATH**
5 **AND SUDDEN UNEXPECTED DEATH IN CHILD-**
6 **HOOD.**

7 Part B of title XI of the Public Health Service Act
8 (42 U.S.C. 241 et seq.) is amended—

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

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

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

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

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

1 porting systems that include data pertaining to sud-
2 den unexpected infant death and sudden unexpected
3 death in childhood, as appropriate, including such
4 systems supported by the Health Resources and
5 Services Administration, in order to—

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

8 “(B) improve the utility of such systems,
9 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 systems available to researchers, in a
19 manner that, at a minimum, protects per-
20 sonal privacy to the extent required by ap-
21 plicable Federal and State law; and

22 “(2) awarding grants or cooperative agreements
23 to States, Indian Tribes, and Tribal organizations
24 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 fatality case reporting systems established for
5 the purpose of conducting research on sudden
6 unexpected infant death and sudden unexpected
7 death in childhood, of samples of tissues or ge-
8 netic materials from autopsies that have been
9 collected pursuant to Federal or State law; or

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

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

1 with other federally-funded programs to reduce infant
2 mortality, as appropriate.

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

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) SUPPORT SERVICES.—

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

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

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

21 “(A) to provide grief counseling, education,
22 home visits, 24-hour hotlines, or information,
23 resources, 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
5 families who have lost a child to sudden unex-
6 pected infant death or sudden unexpected death
7 in 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 di-
12 rect support services and interventions for sud-
13 den unexpected infant death and sudden unex-
14 plained 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
8 childhood’—

9 “(A) means the sudden death of a child
10 who is at least 1 year of age but not more than
11 17 years of age that, when first discovered, did
12 not 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
22 childhood that remains unexplained after a thorough
23 case investigation.

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

1 to be appropriated \$33,000,000 for each of fiscal years
2 2021 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,
6 the Secretary of Health and Human Services shall submit
7 to the Committee on Energy and Commerce of the House
8 of Representatives and the Committee on Health, Edu-
9 cation, Labor, and Pensions of the Senate a report that
10 contains, with respect to the reporting period—

11 (1) information regarding the incidence and
12 number of sudden unexpected infant deaths and
13 sudden unexpected deaths in childhood (including
14 the number of such infant and child deaths that re-
15 main unexplained after investigation), including, to
16 the extent 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 var-
25 ious approaches of reducing and preventing sudden

1 unexpected infant death and sudden unexpected
2 death in 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 “sud-
7 den unexpected infant death” and “sudden unexpected
8 death in childhood” have the meanings given such terms
9 in section 1121 of the Public Health Service Act (as added
10 by section 2).

Passed the House of Representatives September 21,
2020.

Attest:

CHERYL L. JOHNSON,
Clerk.