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.
Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

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

SEC. 2. ADDRESSING SUDDEN UNEXPECTED INFANT DEATH AND SUDDEN UNEXPECTED DEATH IN CHILDHOOD.

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

(1) in the part heading, by striking “SUDDEN INFANT DEATH SYNDROME” and inserting “SUDDEN UNEXPECTED INFANT DEATH, SUDDEN INFANT DEATH SYNDROME, AND SUDDEN UNEXPECTED DEATH IN CHILDHOOD”; and

(2) by inserting before section 1122 the following:

“SEC. 1121. ADDRESSING SUDDEN UNEXPECTED INFANT DEATH AND SUDDEN UNEXPECTED DEATH IN CHILDHOOD.

“(a) IN GENERAL.—The Secretary may develop, support, or maintain programs or activities to address sudden unexpected infant death and sudden unexpected death in childhood, including by—

“(1) continuing to support the Sudden Unexpected Infant Death and Sudden Death in the Young
Case Registry of the Centers for Disease Control and Prevention and other fatality case reporting systems that include data pertaining to sudden unexpected infant death and sudden unexpected death in childhood, as appropriate, including such systems supported by the Health Resources and Services Administration, in order to—

“(A) increase the number of States and jurisdictions participating in such systems; or

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

“(i) making summary data available to the public in a timely manner on the internet website of the Department of Health and Human Services, in a manner that, at a minimum, protects personal privacy to the extent required by applicable Federal and State law; and

“(ii) making the data submitted to such systems available to researchers, in a manner that, at a minimum, protects personal privacy to the extent required by applicable Federal and State law; and
“(2) awarding grants or cooperative agreements to States, Indian Tribes, and Tribal organizations for purposes of—

“(A) supporting fetal and infant mortality and child death review programs for sudden unexpected infant death and sudden unexpected death in childhood, including by establishing such programs at the local level;

“(B) improving data collection related to sudden unexpected infant death and sudden unexpected death in childhood, including by—

“(i) improving the completion of death scene investigations and comprehensive autopsies that include a review of clinical history and circumstances of death with appropriate ancillary testing; and

“(ii) training medical examiners, coroners, death scene investigators, law enforcement personnel, emergency medical technicians, paramedics, emergency department personnel, and others who perform death scene investigations with respect to the deaths of infants and children, as appropriate;
“(C) identifying, developing, and implementing best practices to reduce or prevent sudden unexpected infant death and sudden unexpected death in childhood, including practices to reduce sleep-related infant deaths;

“(D) increasing the voluntary inclusion, in fatality case reporting systems established for the purpose of conducting research on sudden unexpected infant death and sudden unexpected death in childhood, of samples of tissues or genetic materials from autopsies that have been collected pursuant to Federal or State law; or

“(E) disseminating information and materials to health care professionals and the public on risk factors that contribute to sudden unexpected infant death and sudden unexpected death in childhood, which may include information on risk factors that contribute to sleep-related sudden unexpected infant death or sudden unexpected death in childhood.

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

“(c) TECHNICAL ASSISTANCE.—The Secretary shall provide technical assistance to States, Tribes, and Tribal organizations receiving a grant or cooperative agreement under subsection (a)(2) for purposes of carrying out activities funded through the grant or cooperative agreement.

“(d) REPORTING FORMS.—

“(1) IN GENERAL.—The Secretary shall, as appropriate, encourage the use of sudden unexpected infant death and sudden unexpected death in childhood reporting forms developed in collaboration with the Centers for Disease Control and Prevention to improve the quality of data submitted to the Sudden Unexpected Infant Death and Sudden Death in the Young Case Registry, and other fatality case reporting systems that include data pertaining to sudden unexpected infant death and sudden unexpected death in childhood.

“(2) UPDATE OF FORMS.—The Secretary shall assess whether updates are needed to the sudden unexpected infant death investigation reporting form used by the Centers for Disease Control and Prevention in...
order to improve the use of such form with other fatal-
ty case reporting systems supported by the Department of Health and Human Services, and shall make such updates as appropriate.

“(e) SUPPORT SERVICES.—

“(1) IN GENERAL.—The Secretary, acting through the Administrator, shall award grants to national organizations, State and local health departments, community-based organizations, and nonprofit organizations for the provision of support services to families who have had a child die of sudden unexpected infant death or sudden unexpected death in childhood.

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

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

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

“(B) to ensure access to grief and bereave-
ment services;
“(C) to build capacity in professionals working with families who experience a sudden death; or

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

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

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

“(B) demonstrate experience through collaborations and partnerships for delivering services described in paragraph (3).

“(f) DEFINITIONS.—In this section:

“(1) SUDDEN UNEXPECTED INFANT DEATH.—

The term ‘sudden unexpected infant death’—

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

“(B) includes—
“(i) such deaths that are explained;

and

“(ii) such deaths that remain unexplained (which are known as sudden infant death syndrome).

“(2) SUDDEN UNEXPECTED DEATH IN CHILDHOOD.—The term ‘sudden unexpected death in childhood’—

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

“(B) includes—

“(i) such deaths that are explained;

and

“(ii) such deaths that remain unexplained (which are known as sudden unexplained death in childhood).

“(3) SUDDEN UNEXPLAINED DEATH IN CHILDHOOD.—The term ‘sudden unexplained death in childhood’ means a sudden unexpected death in childhood that remains unexplained after a thorough case investigation.

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

SEC. 3. REPORT TO CONGRESS.

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

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

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

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

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

(2) an assessment of the extent to which various
approaches of reducing and preventing sudden unex-
pected infant death and sudden unexpected death in
childhood have been effective; and
(3) a description of the activities carried out
under section 1121 of the Public Health Service Act
(as added by section 2).

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