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 SENATE OF THE UNITED STATES

introduced the following bill; which was read twice and referred to the Committee on

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 Sudden Unexpected Death Act”.

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

Title III of the Public Health Service Act (42 U.S.C. 241 et seq.) is amended by adding at the end the following:

“PART W—SUDDEN UNEXPECTED INFANT DEATH AND SUDDEN UNEXPECTED DEATH IN CHILDHOOD

“SEC. 399oo. DEFINITIONS.

“In this part:

“(1) ADMINISTRATOR.—The term ‘Administrator’ means the Administrator of the Health Resources and Services Administration.

“(2) DEATH SCENE INVESTIGATOR.—The term ‘death scene investigator’ means an individual certified or trained as a death scene investigator by an accredited professional certification board.

“(3) DIRECTOR.—The term ‘Director’ means the Director of the Centers for Disease Control and Prevention.

“(4) STATE.—The term ‘State’ has the meaning given to such term in section 2, except that such term includes Indian tribes and tribal organizations (as such terms are defined in section 4 of the Indian Self-Determination and Education Assistance Act).
“(5) Sudden unexpected infant death; SUID.—The terms ‘sudden unexpected infant death’ and ‘SUID’ mean the sudden death of an infant under 1 year of age that when first discovered did not have an obvious cause. Such terms include those deaths that are later determined to be from explained as well as unexplained causes.

“(6) Sudden unexpected death in childhood.—The term ‘sudden unexpected death in childhood’ means the sudden death of a child who is 1 year of age or older that, when first discovered, did not have an obvious cause. Such term includes those deaths that are later determined to be from an explained cause, and those deaths that remain unexplained after a thorough case investigation that includes a review of the clinical history and circumstances of death and performance of a comprehensive, standardized autopsy with appropriate ancillary testing (which are known as ‘sudden unexplained death in childhood’).

“SEC. 3990O–1. DEATH SCENE INVESTIGATION AND AUTOPSY.

“(a) Investigations.—

“(1) Reporting.—The Secretary, acting through the Director, in consultation with experts
that include board-certified forensic pathologists, medical examiners, coroners, pediatric pathologists, pediatric cardiologists, pediatric neuropathologists and geneticists, and other individuals and groups as the Director determines appropriate, shall revise the Sudden Unexplained Infant Death Investigation Reporting Form of the Centers for Disease Control and Prevention to include doll re-enactments and scene investigation information on sleep-related deaths of children younger than 5, and work to align such form with the National Fatality Review Case Reporting System.

“(2) GRANTS.—The Secretary, acting through the Director, shall award grants to States to enable such States to improve the completion of comprehensive death scene investigations, and reviews of such investigations, for sudden unexpected infant death and sudden unexpected death in childhood.

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

“(4) USE OF FUNDS.—
“(A) IN GENERAL.—A State shall use amounts received under a grant under paragraph (2) to improve the completion of comprehensive death scene investigations for sudden unexpected infant death and sudden unexpected death in childhood, including through the awarding of subgrants to local jurisdictions (which may include subgrants to medical examiners, coroners, and other local entities responsible for conducting autopsies) to be used to implement standard death scene investigation protocols for sudden unexpected infant death and sudden unexpected death in childhood and conduct comprehensive, standardized autopsies.

“(B) PROTOCOLS.—A standard death scene protocol implemented under subparagraph (A) shall include the obtaining of information on—

“(i) current and past medical history of the infant or child and, as relevant, the infant’s or child’s family;

“(ii) the circumstances surrounding the death, including any suspicious circumstances, whether there were any acci-
dental or environmental factors associated
with the death; and

“(iii) in the case of a sleep-related
death, the sleep position and sleep environ-
ment of the infant or child.

“(b) AUTOPSIES.—

“(1) IN GENERAL.—The Secretary, acting
through the Director, shall award grants to States
and local governmental entities to enable such States
and entities to increase the rate at which com-
prehensive, standardized autopsies are performed for
sudden unexpected infant death and sudden unex-
pected death in childhood.

“(2) INFORMED CONSENT.—Grants awarded
under this subsection may be used for studies and
demonstration projects to increase the rate of con-
sent among families of deceased children for the in-
cclusion of genetic or tissue samples collected during
autopsy in registries established for the purposes of
conducting research into sudden unexpected infant
deaths and sudden unexpected death in childhood.

“(3) APPLICATION.—To be eligible to receive a
grant under paragraph (1), an eligible entity de-
scribed in such paragraph shall submit to the Sec-
retary an application that includes—
“(A) a description of the methods to be studied or tested to increase the rate of consent among families of deceased children for the inclusion of genetic or tissue samples collected during autopsy;

“(B) information about the governmental and nongovernmental entities with whom the eligible entity will partner; and

“(C) any additional information as the Secretary may require.

“(4) COMPREHENSIVE AUTOPSY.—For purposes of this subsection, a comprehensive, standardized autopsy includes, as appropriate, a full external and internal examination, including microscopic examination, of all major organs and tissues including the brain, complete radiographs, vitreous fluid analysis, photo documentation, metabolic testing, toxicology screening, and, when indicated, selected genetic and microbiology analyses of the infant or child involved.

“(c) GENETIC ANALYSIS.—The Director, in consultation with medical examiners, coroners, forensic pathologists, geneticists, researchers, public health officials, and other individuals and groups as the Director determines appropriate, shall develop recommendations for a standard protocol for use in determining when to utilize genetic
analysis, and standard protocols for the collection and
storage of specimens suitable for genetic analysis.

“(d) Authorization of Appropriations.—To
carry out this section, there is authorized to be appro-
piated $8,000,000 for each of fiscal years 2019 through
2023.

“SEC. 39900–2. TRAINING.

“(a) Grants.—The Secretary, acting through the
Director, shall award grants to eligible entities for the pro-
vision of training on death scene investigation specific for
sudden unexpected infant death and sudden unexpected
death in childhood.

“(b) Eligible Entities.—To be eligible to receive
a grant under subsection (a), an entity shall—

“(1) be—

“(A) a State or local government entity; or
“(B) a nonprofit private entity;

“(2) submit to the Secretary an application at
such time, in such manner, and containing such in-
formation as the Secretary may require; and

“(3) make publishing training materials devel-
oped using a grant awarded under subsection (a)
available on an internet website and at no charge to
attendees of training under subsection (c)(1).
“(c) USE OF FUNDS.—An eligible entity shall use amounts received under a grant under this section to—

“(1) provide training to medical examiners, coroners, death scene investigators, law enforcement personnel, justices of the peace, emergency medical technicians, paramedics, or emergency department personnel concerning death scene investigations for sudden unexpected infant death and sudden unexpected death in childhood, including the use of standard death scene investigation protocols that include information on—

“(A) current and past medical history of the infant or child and, as relevant, the infant’s or child’s family;

“(B) the circumstances surrounding the death, including any suspicious circumstances;

“(C) whether there were any accidental or environmental factors associated with the death; and

“(D) in the case of a sleep-related death, the sleep position and sleep environment of the infant or child;

“(2) provide training directly to individuals who are responsible for conducting and reviewing death
scene investigations for sudden unexpected infant
death and sudden unexpected death in childhood;

“(3) provide training to multidisciplinary teams,
including teams that have a medical examiner or
coroner, death scene investigator, law enforcement
representative, and an emergency medical technician
or paramedic;

“(4) in the case of national and State-based
grantees that are comprised of medical examiners,
coroners, death scene investigators, law enforcement
personnel, or emergency medical technicians and
paramedics, integrate training under the grant on
death scene investigation of sudden unexpected in-
fant death and sudden unexpected death in child-
hood into professional accreditation and training
programs; or

“(5) in the case of State and local government
entity grantees, obtain equipment, including scene
investigation kits, to aid in the completion of stand-
ard death scene investigation.

“(d) Authorization of Appropriations.—To
carry out this section, there is authorized to be appro-
priated $2,000,000 for each of fiscal years 2019 through
2023.
“SEC. 3990O–3. INFANT AND CHILD DEATH REVIEW.

“(a) Prevention.—

“(1) Core capacity grants.—The Secretary, acting through the Administrator and in consultation with the Associate Commissioner of the Children’s Bureau of the Administration for Children and Families, shall award grants to States to build and strengthen State capacity, and enable States to support local governments’ capacity, so as to review 100 percent of all infant and child deaths, and to develop and implement prevention strategies, as appropriate.

“(2) Planning grants.—The Secretary, acting through the Administrator, shall award planning grants to States in which the only infant and child death review programs are statewide, for the development of local infant and child death review programs and prevention strategies.

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

“(4) Technical assistance.—The Secretary, acting through the Administrator, shall provide technical assistance to assist States—
“(A) in developing the capacity for comprehensive infant and child death review programs, including the development of best practices for the implementation of such programs; and

“(B) in maintaining the National Fatality Review Case Reporting System.

“(b) Authorization of Appropriations.—To carry out this section, there is authorized to be appropriated $15,000,000 for each of fiscal years 2019 through 2023.

“SEC. 39900–4. ENHANCING THE NATIONAL FATALITY REVIEW CASE REPORTING SYSTEM.

“(a) In General.—The Secretary, acting through the Director and in consultation with the National Fatality Review Case Reporting System, national health organizations, and professional societies with experience and expertise relating to reducing sudden unexpected infant death and sudden unexpected death in childhood, shall maintain current efforts of the National Fatality Review Case Reporting System so as to provide population-based data on unexpected deaths occurring for infants or children under age 18, in order to facilitate the understanding of the root causes, rates, trends, and geographic variations
of sudden unexpected infant death and sudden unexpected
death in childhood.

“(b) Compilation and Availability of Data.—
The Secretary shall—

“(1) compile the data submitted under this sec-
tion;

“(2) make summary data available to the public
in a timely manner on an appropriate internet
website in a format that is useful to the public; and

“(3) make data submitted under this section
available, in a manner that protects the privacy of
individuals involved, to individuals or entities con-
ducting research into the causes of, or prevention
methods for, sudden unexpected infant death and
sudden unexpected death in childhood.

“(c) Authorization of Appropriations.—To
carry out this section, there is authorized to be appro-
priated $1,000,000 for each of fiscal years 2019 through
2023.

“SEC. 39900–5. GRANTS TO SUPPORT INFANT SAFE SLEEP.

“(a) In General.—The Secretary, acting through
the Administrator, shall award grants to national organi-
izations, community-based organizations, municipal public
safety departments, and nonprofit organizations for the
provision of evidence-based approaches for educational
programs, and outreach activities focused on decreasing
the risk factors that contribute to sleep-related SUID.

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

“(c) Use of Funds.—Amounts received under a
grant awarded under subsection (a) may be used to—

“(1) provide outreach and education services di-
rectly to parents and families, which—

“(A) may include home visits, 24-hour hot-
lines, internet-based educational materials, mo-
bile health technologies, and social marketing
campaigns;

“(B) shall apply current safe sleep guide-
lines published by a professional pediatric orga-
nization; and

“(C) may provide safe sleep-related prod-
ucts to families at no cost or at reduced cost
that have published, peer-reviewed evidence to
support safer sleep environments for infants
through age one; or

“(2) build capacity in professionals working
with families to support safe sleep.
“(d) SAFE-SLEEP PRODUCTS.—Any product related to safe sleep for an infant that is provided under subsection (c)(1)(C) shall—

“(1) be in compliance with current safe sleep guidelines published by a professional pediatric organization;

“(2) be intended for use by the infant through age one; and

“(3) be covered by, and be in compliance with, a regulation or mandatory standard promulgated by the Consumer Product Safety Commission.

“(e) PREFERENCE.—In awarding grants under subsection (a), the Secretary shall give preference to applicants that have a proven history of developing or delivering interventions for infants and families to support safe sleep, include plans to report evidence of program outcomes, and can demonstrate experience through collaborations and partnerships for delivering services throughout a State or region.

“(f) SET-ASIDE.—Not more than 5 percent of the amount of funds appropriated to carry out this section may be used to conduct research into the behavioral risks that lead to unsafe sleep practices and ways to mitigate those risks.
“(g) Authorization of Appropriations.—To carry out this section, there is authorized to be appropriated $5,000,000 for fiscal year 2019 and $7,000,000 for each of fiscal years 2020 through 2023.”.

SEC. 3. SENSE OF CONGRESS.

It is the sense of Congress that additional research is needed to improve the understanding of the epidemiology of sudden unexpected infant and childhood deaths that remain unexplained following a comprehensive, standardized autopsy and appropriate ancillary testing.

SEC. 4. REPORT TO CONGRESS.

Not later than 1 year after the date of enactment of this Act, and biennially thereafter, the Secretary of Health and Human Services, acting through the Director of the Centers for Disease Control and Prevention and in consultation with the Director of the National Institutes of Health and the Administrator of the Health Resources and Services Administration, shall submit to the Committee on Health, Education, Labor, and Pensions of the Senate and the Committee on Energy and Commerce of the House of Representatives a report that contains, with respect to the preceding reporting period—

(1) information regarding the absolute number and incidence of sudden unexpected infant death,
pected death in childhood, information about the
number of such infant and child deaths that remain
unexplained, information about such conditions by
racial and ethnic groups, information about such
conditions by State, aggregate information obtained
from death scene investigations and autopsies, and
recommendations for reducing the incidence of sud-
den unexpected infant death and sudden unexpected
death in childhood;

(2) an assessment of the extent to which var-
ious approaches of preventing sudden unexpected in-
fant death and sudden unexpected death in child-
hood have been effective;

(3) a description of the activities carried out
under part W of title III of the Public Health Serv-
ice Act (as added by section 2); and

(4) any recommendations of the Secretary re-
garding such part W.