

One Hundred Sixteenth Congress
of the
United States of America

AT THE SECOND SESSION

*Begun and held at the City of Washington on Friday,
the third day of January, two thousand and twenty*

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.

*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. AMENDMENT TO THE PUBLIC HEALTH SERVICE ACT.

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 registries or systems; and

“(B) improve the utility of such registries or 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 registries or 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 registries 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 and for which the parent or guardian has provided informed consent for inclusion in such registries;

“(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; or

“(F) providing information, referrals, or peer or follow-up support services to families who have experienced 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 and child 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 the program in accordance with this section.

“(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 fatality case reporting systems supported by the Department of Health and Human Services, and shall make such updates as appropriate.

“(e) DEFINITIONS.—In this section:

“(1) SUDDEN INFANT DEATH SYNDROME.—The term ‘sudden infant death syndrome’ means a sudden unexpected infant death that remains unexplained after a thorough case investigation.

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

“(3) SUDDEN UNEXPECTED DEATH IN CHILDHOOD.—The term ‘sudden unexpected death in childhood’ 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. Such term includes such deaths that are explained, as well as deaths that remain unexplained (which are known as sudden unexplained death in childhood).

“(4) 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.

“(f) AUTHORIZATION OF APPROPRIATIONS.—For the purpose of carrying out this section, there is authorized to be appropriated \$12,000,000 for each of fiscal years 2022 through 2026.”.

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 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 reporting period—

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

(A) a summary of such information by racial and ethnic group, and by State;

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

(C) recommendations for reducing the incidence 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 unexpected 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).

Speaker of the House of Representatives.

*Vice President of the United States and
President of the Senate.*