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

FEBRUARY 13, 2013

Mr. Pallone (for himself and Mr. King of New York) introduced the following bill; which was referred to the Committee on Energy and Commerce

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 Representa-

Section 1. Short Title.

This Act may be cited as the “Sudden Unexpected Death Data Enhancement and Awareness Act”.

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5 Death Data Enhancement and Awareness Act”.

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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 UNEXPLAINED 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 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 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 unexplained as well as unexplained causes.

“(6) Sudden unexplained death in childhood; SUDC.—The terms ‘sudden unexplained death in childhood’ and ‘SUDC’ mean the sudden death of a child older than 1 year of age which remains unexplained after a thorough case investigation that includes a review of the clinical history and circumstances of death and performance of a complete autopsy with appropriate ancillary testing.

“SEC. 39900–1. DEATH SCENE INVESTIGATION AND AUTOPSY.

“(a) INVESTIGATIONS.—

“(1) 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 for sudden unexpected infant death and sudden unexplained death in childhood.
“(2) APPLICATION.—To be eligible to receive a grant under paragraph (1), a State 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.—

“(A) IN GENERAL.—A State shall use amounts received under a grant under paragraph (1) to improve the completion of comprehensive death scene investigations for sudden unexpected infant death and sudden unexplained death in childhood, including through the awarding of subgrants to local jurisdictions to be used to implement standard death scene investigation protocols for sudden unexpected infant death and sudden unexplained 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 current and past medical history of the infant/child, the circumstances surrounding the death including any suspicious circumstances, the sleep position and sleep environment of the
infant/child, and whether there were any acci-
dental or environmental factors associated with
the death. The Director in consultation with
medical examiners, coroners, death scene inves-
tigators, law enforcement, emergency medical
technicians and paramedics, public health agen-
cies, and other individuals or groups determined
necessary by the Director shall develop a stand-
ard death scene protocol for children from 1 to
4 years of age, using existing protocols devel-
oped for SUID.

“(b) AUTOPSIES.—

“(1) IN GENERAL.—The Secretary, acting
through the Director, shall award grants to States
to enable such States to increase the rate at which
comprehensive, standardized autopsies are per-
formed for sudden unexpected infant death and sud-
den unexplained death in childhood.

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

“(3) COMPREHENSIVE AUTOPSY.—For purposes
of this subsection, a comprehensive autopsy shall in-
clude 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, selected microbiology when indicated, metabolic testing, and toxicology screening of the infant or child involved.

“(4) GUIDELINES.—The Director, in consultation with board certified forensic pathologists, medical examiners, coroners, pediatric pathologists, pediatric cardiologists, pediatric neuropathologists and geneticists, and other individuals and groups determined necessary by the Director shall develop national guidelines for a standard autopsy protocol for sudden unexpected infant death and sudden unexplained death in childhood. The Director shall ensure that the majority of such consultation is with board certified forensic pathologists, medical examiners, and coroners. The Director is encouraged to seek additional input from child abuse experts, bereavement specialists, parents, and public health agencies on nonmedical aspects of the autopsy guidelines. In developing such protocol, the Director shall consider autopsy protocols used by State and local jurisdictions.
“(c) STUDY ON GENETIC TESTING.—The Director, in consultation with medical examiners, coroners, forensic pathologists, geneticists, researchers, public health officials, and other individuals and groups determined necessary by the Director, shall commission a study to determine the benefits and appropriateness of genetic testing for infant and early childhood deaths that remain unexplained after a complete death scene investigation and comprehensive, standardized autopsy. Such study shall include recommendations on developing a standard protocol for use in determining when to utilize genetic testing and standard protocols for the collection and storage of specimens suitable for genetic testing.

“(d) AUTHORIZATION OF APPROPRIATIONS.—There is authorized to be appropriated $8,000,000 for each of fiscal years 2014 through 2018 to carry out this section.

“SEC. 39900–2. TRAINING.

“(a) GRANTS.—The Secretary, acting through the Director, shall award grants to eligible entities for the provision of training on death scene investigation specific for SUID and SUDD.

“(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; and

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

“(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, and emergency medical technicians or paramedics concerning death scene investigations for SUID and SUDC, including the use of standard death scene investigation protocols that include information on the current and past medical history of the infant/child, the circumstances surrounding the death including any suspicious circumstances, the sleep position and sleep environment of the infant/child, and whether there were any accidental or environmental factors associated with the death;

“(2) provide training directly to individuals who are responsible for conducting and reviewing death scene investigations for sudden unexpected infant death and sudden unexplained 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 SUID and SUDC into professional accreditation and training programs;

“(5) in the case of State and local government entity grantees, obtain equipment, including computer equipment, to aid in the completion of standard death scene investigation; or

“(6) conduct training activities for medical examiners, coroners, and forensic pathologists concerning standard autopsy protocols for sudden unexpected infant death and sudden unexplained death in childhood and integrate the training under the grant on standard autopsy protocols in SUID and SUDC into professional accreditation and training programs.

“(d) AUTHORIZATION OF APPROPRIATIONS.—There is authorized to be appropriated to carry out this section $2,000,000 for each of fiscal years 2014 through 2018.
"SEC. 399OO–3. CHILD DEATH REVIEW.

"(a) PREVENTION.—

"(1) CORE CAPACITY GRANTS.—The Secretary, acting through the Administrator, shall award grants to States to build and strengthen State capacity and implement State and local child death review programs and prevention strategies.

"(2) PLANNING GRANTS.—The Secretary, acting through the Administrator, shall award planning grants to States that have no existing child death review program or States in which the only child death review programs are State-based, for the development of local 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 child death review programs, including the development of best practices for the implementation of such programs; and
“(B) in maintaining the national child
death case reporting system.

“(b) Authorization of Appropriations.—There
is authorized to be appropriated $7,000,000 for each of
fiscal years 2014 through 2018 to carry out subsection
(a).

“SEC. 399OO–4. ENHANCING THE NATIONAL CHILD DEATH
CASE REPORTING SYSTEM.

“(a) In General.—The Secretary, acting through
the Director and in consultation with the national child
death case reporting system, national health organiza-
tions, and professional societies with experience and exper-
tise relating to reducing SUID and SUDC, shall modify
such national death case reporting system, in accordance
with subsection (b), to assure that such system provides
for population-based data for ages 0 through 4 years of
age and facilitates the understanding of the root causes,
rates, and trends of SUID and SUDC with respect to such
ages.

“(b) Goals of Modified National Child Death
Case Reporting System.—The modifications under
subsection (a) to the national child death case reporting
system shall facilitate the collection, analysis, and dissemi-
nation of data by—
“(1) implementing a surveillance and monitoring system based on thorough and complete death scene investigation data, clinical history, and autopsy findings;

“(2) collecting standardized information about the environmental, medical, genetic, and social circumstances of death (including sleep environment and quality of the death scene investigation) if determined that such may correlate with infant and early childhood deaths, as well as information from other law enforcement, medical examiner, coroner, emergency medical services (EMS), medical records, and vital records (if possible);

“(3) supporting multidisciplinary infant and early childhood death reviews such as those performed by child death review committees to collect and review the standardized information and accurately and consistently classify and characterize SUID and SUDC;

“(4) facilitating the sharing of information to improve the public reporting of surveillance and vital statistics describing the epidemiology of SUID and SUDC; and

“(5) utilizing current infrastructure of existing surveillance systems.
'(c) Authorization of Appropriations.—There is authorized to be appropriated to carry out this section $3,000,000 for each of fiscal years 2014 through 2018.

SEC. 39900–5. PUBLIC AWARENESS AND EDUCATION CAMPAIGN.

(a) Establishment.—The Secretary, acting through the Administrator and in consultation with the Director and the Director of the National Institutes of Health, shall establish and implement a culturally competent research-based public health awareness and education campaign to provide information that is focused on decreasing the risk factors that contribute to sudden unexpected infant death and sudden unexplained death in childhood, including educating individuals and organizations about safe sleep environments, sleep positions, and reducing exposure to smoking during pregnancy and after birth.

(b) Targeted Populations.—The campaign under subsection (a) shall be designed to reduce health disparities through the targeting of populations with high rates of sudden unexpected infant death and sudden unexplained death in childhood.

(c) Consultation.—In establishing and implementing the campaign under subsection (a), the Secretary shall consult with national organizations representing
health care providers, including nurses and physicians, parents, child care providers, children’s advocacy and safety organizations, maternal and child health programs and women’s, infants’, and children’s nutrition professionals, and other individuals and groups determined necessary by the Secretary for such establishment and implementation.

“(d) Grants.—

“(1) In general.—In carrying out the campaign under subsection (a), the Secretary shall award grants to national organizations, State and local health departments, and community-based organizations for the conduct of education and outreach programs for health care providers, parents, child care providers, public health agencies, and community organizations.

“(2) Application.—To be eligible to receive a grant under paragraph (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.

“(e) Authorization of Appropriations.—There is authorized to be appropriated to carry out this section $7,000,000 for fiscal year 2014 and $5,000,000 for each of fiscal years 2015 through 2018.
“SEC. 399OO–6. GRANTS FOR SUPPORT SERVICES.

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

“(b) Application.—To be eligible to receive a grant under subsection (a), an entity shall submit to the Secretary 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 provide grief counseling, education, home visits, 24-hour hotlines, and support groups for families who have lost a child to sudden unexpected infant death or sudden unexplained death in childhood.

“(d) Preference.—In awarding grants under subsection (a), the Secretary shall give preference to community-based applicants that have a proven history of effective direct support services and interventions for sudden unexpected infant death and sudden unexplained death in childhood and can demonstrate experience through collaborations and partnerships for delivering services throughout a State or region.
“(e) Authorization of Appropriations.—There is authorized to be appropriated to carry out this section $500,000 for each of fiscal years 2014 through 2018.

“SEC. 399OO–7. EVALUATION OF STATE AND REGIONAL NEEDS.

“(a) In General.—The Secretary, acting through the Director and in consultation with the Administrator, shall conduct a needs assessment on a State and regional basis of the availability of personnel, training, technical assistance, and resources for investigating and determining sudden unexpected infant death and sudden unexplained death in childhood and make recommendations to increase collaboration on a State and regional level for investigation and determination.

“(b) Authorization of Appropriations.—There is authorized to be appropriated to carry out this section, $250,000 for each of fiscal years 2014 through 2018.”.

SEC. 3. ENHANCING PUBLIC HEALTH ACTIVITIES RELATED TO STILLBIRTH.

Part P of title III of the Public Health Service Act (42 U.S.C. 280g et seq.) is amended by adding at the end the following:
“SEC. 399V–6. ENHANCING PUBLIC HEALTH ACTIVITIES RELATED TO STILLBIRTH.

“(a) GRANTS.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall award grants to eligible States and metropolitan areas to enhance and expand surveillance efforts to collect thorough and complete epidemiologic information on stillbirths, including through the utilization of the infrastructure of existing surveillance systems (including vital statistics systems).

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

“(1) be a State or a major metropolitan area (as defined by the Secretary); and

“(2) submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require, including—

“(A) an assurance that the applicant will implement the standardized surveillance protocol developed under subsection (c); and

“(B) a description of the infrastructure of existing surveillance systems in the State or major metropolitan area, as applicable.

“(c) SURVEILLANCE PROTOCOL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall—
“(1) provide for the continued development and dissemination of a standard protocol for stillbirth data collection and surveillance, in consultation with representatives of health and advocacy organizations, State and local governments, and other interested entities determined appropriate by the Secretary;

“(2) monitor trends and identify potential risk factors for further study using existing sources of surveillance data and expanded sources of data from targeted surveillance efforts, and methods for the evaluation of stillbirth prevention efforts; and

“(3) develop and evaluate methods to link existing data to provide more complete information for research into the causes and conditions associated with stillbirth.

“(d) POSTMORTEM EVALUATION AND DATA COLLECTION.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention and in consultation with physicians, nurses, pathologists, geneticists, parents, and other groups determined necessary by the Director, shall develop guidelines for increasing the performance and data collection of postmortem stillbirth evaluation, including conducting and reimbursing autopsies, placental histopathology, and cytogenetic testing. The guide-
lines should take into account cultural competency issues related to postmortem stillbirth evaluation.

“(e) Public Health Programmatic Activities Related to Stillbirth.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall—

“(1) develop behavioral surveys for women experiencing stillbirth, using existing State-based infrastructure for pregnancy-related information gathering; and

“(2) increase the technical assistance provided to States, Indian tribes, territories, and local communities to enhance capacity for improved investigation of medical and social factors surrounding stillbirth events.

“(f) Public Education and Prevention Programs.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention and in consultation with health care providers, public health organizations, maternal and child health programs, parents, and other groups deemed necessary by the Director, shall directly or through grants, cooperative agreements, or contracts to eligible entities, develop and conduct evidence-based public education and prevention programs aimed at reducing the occurrence of stillbirth overall and addressing
the racial and ethnic disparities in its occurrence, including—

“(1) public education programs, services, and demonstrations which are designed to increase general awareness of stillbirths; and

“(2) the development of tools for the education of health professionals and women concerning the known risk factors for stillbirth, promotion of fetal movement awareness, and the importance of early and regular prenatal care to monitor the health and development of the fetus up to and during delivery.

“(g) TASK FORCE.—The Secretary, in consultation with the Director of the National Institutes of Health, the Director of the Centers for Disease Control and Prevention, and health care providers, researchers, parents, and other groups deemed necessary by the Directors, shall establish a task force to develop a national research plan to determine the causes of, and how to prevent, stillbirth.

“(h) GRANTS FOR SUPPORT SERVICES.—

“(1) IN GENERAL.—The Secretary, acting through the Administrator of the Health Resources and Services Administration, shall award grants to national organizations, State and local health departments, and community-based organizations, for
the provisions of support services to families who have experienced stillbirth.

“(2) Application.—To be eligible to receive a grant under subsection (a), 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 subsection (a) may be used to provide grief counseling, education, home visits, 24-hour hotlines, and support groups for families who have experienced stillbirth.

“(4) Preference.—In awarding grants under subsection (a), the Secretary shall give preference to applicants that are community-based organizations that have a proven history of providing effective direct support services and interventions related to stillbirths and can demonstrate experience through collaborations and partnerships for delivering services throughout a State or region.

“(i) Definitions.—In this section:

“(1) The term ‘State’ has the meaning given to such term in section 2, except that such term includes tribes and tribal organizations (as such terms
are defined in section 4 of the Indian Self-Determination and Education Assistance Act).

“(2) The term ‘stillbirth’ means a spontaneous, not induced, pregnancy loss 20 weeks or later after gestation, or if the age of the fetus is not known, then a fetus weighing 350 grams or more.

“(j) Authorization of Appropriations.—There is authorized to be appropriated to carry out this section, $3,000,000 for each of fiscal years 2014 through 2018.”.

SEC. 4. REPORT TO CONGRESS.

Not later than 2 years after the date of enactment of this Act, 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 Congress a report describing the progress made in implementing this Act (and the amendments made by this Act).