H. R. 4571

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 12, 2016

Ms. Moore (for herself, Ms. Jackson Lee, Mr. Grijalva, Mr. Ryan of Ohio, Mr. Hastings, Mr. Rangel, Mrs. Beatty, and Ms. Bordallo) 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 Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the “Reducing Unexpected Deaths in Infants and Children Act of 2016”.

SEC. 2. FINDINGS.

Congress finds as follows:
(1) Nearly 3,500 infants die suddenly and unexpectedly every year.

(2) Infants born to low-income women are more likely to die before their first birthday than infants born in higher-income households.

(3) Non-Hispanic Black infants are more than twice as likely to die of Sudden Unexpected Infant Death compared to non-Hispanic White infants.

(4) Disparities in sudden unexpected infant deaths account for 14 percent of the infant mortality gap between non-Hispanic Black infants compared to non-Hispanic White infants.

(5) Preterm birth and low birth weight may be contributing factors in deaths from Sudden Infant Death Syndrome, which is a type of sudden unexpected infant death and the leading cause of postneonatal deaths.

(6) Timely prenatal care and appropriate birth spacing can reduce the risks of early delivery and low birth weight.

(7) Women can reduce the risk of infant mortality to their infants by improving their own health, both preconception and during pregnancy.

(8) The American Academy of Pediatrics recommends regular prenatal care as a strategy for
preventing SIDS, noting that there is “substantial epidemiologic evidence linking a lower risk of SIDS for infants whose mothers obtain regular prenatal care”.

SEC. 3. 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 explained 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 who is 1 year of age or older, 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. 399OO–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 accidental or environmental factors associated with the death. The Director in consultation with medical examiners, coroners, death scene investigators, law enforcement, emergency medical technicians and paramedics, public health agencies, and other individuals or groups determined necessary by the Director shall develop a standard death scene protocol for children from 1 to 4 years of age, using existing protocols developed 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 performed 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 Sec-
retary may require.

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

“(4) GUIDELINES.—The Director, in consulta-
tion with board certified forensic pathologists, med-
ical examiners, coroners, pediatric pathologists, pedi-
atrie cardiologists, pediatric neuropathologists and geneticists, and other individuals and groups deter-
mined necessary by the Director shall develop na-
tional guidelines for a standard autopsy protocol for sudden unexpected infant death and sudden unex-
plained death in childhood. The Director shall en-
sure that the majority of such consultation is with board certified forensic pathologists, medical exam-
iners, and coroners. The Director is encouraged to seek additional input from child abuse experts, be-
reavement 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) Authorization of Appropriations.—There is authorized to be appropriated $8,000,000 for each of fiscal years 2017 through 2021 to carry out this section.

“SEC. 3990O–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 SUDC.

“(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, justices of the peace, and emergency med-
ical technicians or paramedics concerning death
scene investigations for SUID and SUDC, including
the use of standard death scene investigation proto-
cols that include information on the current and
past medical history of the infant/child, the cir-
cumstances surrounding the death including any
suspicous 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 2017 through 2021.

“SEC. 39900–3. INFANT AND 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 infant and 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 infant or child death review program or States in which the only infant and child death review programs are State-based, 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 infant and child death case reporting system.

“(b) Authorization of Appropriations.—There is authorized to be appropriated $7,000,000 for each of
fiscal years 2017 through 2021 to carry out subsection (a).

“SEC. 39900–4. GRANTS FOR SUPPORT SERVICES.

“(a) 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 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, ensure access to grief and bereavement services, build capacity in professionals working with families who experience a sudden death, 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 effec-
tive direct support services and interventions for sudden
unexpected infant death and sudden unexplained death in
childhood and can demonstrate experience through col-
laborations 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
$1,000,000 for each of fiscal years 2017 through 2021.

“SEC. 39900–5. 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 deter-
mining sudden unexpected infant death and sudden unex-
plained death in childhood and make recommendations to
increase collaboration on a State and regional level for in-
vestigation and determination.

“(b) Authorization of Appropriations.—There
is authorized to be appropriated to carry out this section
$250,000 for each of fiscal years 2017 through 2021.”.
SEC. 4. 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 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; 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.
“(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 evalua-
tion, including conducting and reimbursing autopsies, placental histopathology, and cytogenetic testing. The guidelines 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;

“(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; and

“(3) establish best practices for home visits after the death of a child, using existing standards for such best practices, as available.

“(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 con-
tracts 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, includ-
ing—

“(1) public education programs, services, and
demonstrations which are designed to increase gen-
eral 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 Preven-
tion, and health care providers, researchers, parents, and
other groups deemed necessary by the Directors, shall es-
tablish 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 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.

“(3) USE OF FUNDS.—Amounts received under a grant awarded under paragraph (1) may be used to provide grief counseling, education, home visits, 24-hour hotlines, ensure access to grief and bereavement services, build capacity in professionals working with families who experience a sudden death, and support groups for families who have experienced stillbirth.

“(4) PREFERENCE.—In awarding grants under paragraph (1), 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 2017 through 2021.”.