

114TH CONGRESS
2D SESSION

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.

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 “Reducing Unexpected
5 Deaths in Infants and Children Act of 2016”.

6 **SEC. 2. FINDINGS.**

7 Congress finds as follows:

1 (1) Nearly 3,500 infants die suddenly and un-
2 expectedly every year.

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

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

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

13 (5) Preterm birth and low birth weight may be
14 contributing factors in deaths from Sudden Infant
15 Death Syndrome, which is a type of sudden unex-
16 pected infant death and the leading cause of
17 postneonatal deaths.

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

21 (7) Women can reduce the risk of infant mor-
22 tality to their infants by improving their own health,
23 both preconception and during pregnancy.

24 (8) The American Academy of Pediatrics rec-
25 ommends regular prenatal care as a strategy for

1 preventing SIDS, noting that there is “substantial
2 epidemiologic evidence linking a lower risk of SIDS
3 for infants whose mothers obtain regular prenatal
4 care”.

5 **SEC. 3. AMENDMENT TO THE PUBLIC HEALTH SERVICE**
6 **ACT.**

7 Title III of the Public Health Service Act (42 U.S.C.
8 241 et seq.) is amended by adding at the end the fol-
9 lowing:

10 **“PART W—SUDDEN UNEXPECTED INFANT DEATH**
11 **AND SUDDEN UNEXPLAINED DEATH IN**
12 **CHILDHOOD**

13 **“SEC. 3990O. DEFINITIONS.**

14 “In this part:

15 “(1) ADMINISTRATOR.—The term ‘Adminis-
16 trator’ means the Administrator of the Health Re-
17 sources and Services Administration.

18 “(2) DEATH SCENE INVESTIGATOR.—The term
19 ‘death scene investigator’ means an individual cer-
20 tified as a death scene investigator by an accredited
21 professional certification board.

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

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

6 “(5) SUDDEN UNEXPECTED INFANT DEATH;
7 SUID.—The terms ‘sudden unexpected infant death’
8 and ‘SUID’ mean the sudden death of an infant
9 under 1 year of age that when first discovered did
10 not have an obvious cause. Such terms include those
11 deaths that are later determined to be from ex-
12 plained as well as unexplained causes.

13 “(6) SUDDEN UNEXPLAINED DEATH IN CHILD-
14 HOOD; SUDC.—The terms ‘sudden unexplained death
15 in childhood’ and ‘SUDC’ mean the sudden death of
16 a child who is 1 year of age or older, which remains
17 unexplained after a thorough case investigation that
18 includes a review of the clinical history and cir-
19 cumstances of death and performance of a complete
20 autopsy with appropriate ancillary testing.

21 **“SEC. 39900-1. DEATH SCENE INVESTIGATION AND AU-**
22 **TOPSY.**

23 “(a) INVESTIGATIONS.—

24 “(1) GRANTS.—The Secretary, acting through
25 the Director, shall award grants to States to enable

1 such States to improve the completion of comprehen-
2 sive death scene investigations for sudden unex-
3 pected infant death and sudden unexplained death in
4 childhood.

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

10 “(3) USE OF FUNDS.—

11 “(A) IN GENERAL.—A State shall use
12 amounts received under a grant under para-
13 graph (1) to improve the completion of com-
14 prehensive death scene investigations for sud-
15 den unexpected infant death and sudden unex-
16 plained death in childhood, including through
17 the awarding of subgrants to local jurisdictions
18 to be used to implement standard death scene
19 investigation protocols for sudden unexpected
20 infant death and sudden unexplained death in
21 childhood and conduct comprehensive, stand-
22 ardized autopsies.

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

1 on current and past medical history of the in-
2 fant/child, the circumstances surrounding the
3 death including any suspicious circumstances,
4 the sleep position and sleep environment of the
5 infant/child, and whether there were any acci-
6 dental or environmental factors associated with
7 the death. The Director in consultation with
8 medical examiners, coroners, death scene inves-
9 tigators, law enforcement, emergency medical
10 technicians and paramedics, public health agen-
11 cies, and other individuals or groups determined
12 necessary by the Director shall develop a stand-
13 ard death scene protocol for children from 1 to
14 4 years of age, using existing protocols devel-
15 oped for SUID.

16 “(b) AUTOPSIES.—

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

23 “(2) APPLICATION.—To be eligible to receive a
24 grant under paragraph (1), a State shall submit to
25 the Secretary an application at such time, in such

1 manner, and containing such information as the Sec-
2 retary may require.

3 “(3) COMPREHENSIVE AUTOPSY.—For purposes
4 of this subsection, a comprehensive autopsy shall in-
5 clude genetic testing and a full external and internal
6 examination, including microscopic examination, of
7 all major organs and tissues including the brain,
8 complete radiographs, vitreous fluid analysis, photo
9 documentation, selected microbiology when indi-
10 cated, metabolic testing, and toxicology screening of
11 the infant or child involved.

12 “(4) GUIDELINES.—The Director, in consulta-
13 tion with board certified forensic pathologists, med-
14 ical examiners, coroners, pediatric pathologists, pedi-
15 atric cardiologists, pediatric neuropathologists and
16 geneticists, and other individuals and groups deter-
17 mined necessary by the Director shall develop na-
18 tional guidelines for a standard autopsy protocol for
19 sudden unexpected infant death and sudden unex-
20 plained death in childhood. The Director shall en-
21 sure that the majority of such consultation is with
22 board certified forensic pathologists, medical exam-
23 iners, and coroners. The Director is encouraged to
24 seek additional input from child abuse experts, be-
25 reavement specialists, parents, and public health

1 agencies on nonmedical aspects of the autopsy guide-
2 lines. In developing such protocol, the Director shall
3 consider autopsy protocols used by State and local
4 jurisdictions.

5 “(c) AUTHORIZATION OF APPROPRIATIONS.—There
6 is authorized to be appropriated \$8,000,000 for each of
7 fiscal years 2017 through 2021 to carry out this section.

8 **“SEC. 39900-2. TRAINING.**

9 “(a) GRANTS.—The Secretary, acting through the
10 Director, shall award grants to eligible entities for the pro-
11 vision of training on death scene investigation specific for
12 SUID and SUDC.

13 “(b) ELIGIBLE ENTITIES.—To be eligible to receive
14 a grant under subsection (a), an entity shall—

15 “(1) be—

16 “(A) a State or local government entity; or

17 “(B) a nonprofit private entity; and

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

21 “(c) USE OF FUNDS.—An eligible entity shall use
22 amounts received under a grant under this section to—

23 “(1) provide training to medical examiners,
24 coroners, death scene investigators, law enforcement
25 personnel, justices of the peace, and emergency med-

1 ical technicians or paramedics concerning death
2 scene investigations for SUID and SUDC, including
3 the use of standard death scene investigation proto-
4 cols that include information on the current and
5 past medical history of the infant/child, the cir-
6 cumstances surrounding the death including any
7 suspicious circumstances, the sleep position and
8 sleep environment of the infant/child, and whether
9 there were any accidental or environmental factors
10 associated with the death;

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

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

20 “(4) in the case of national and State-based
21 grantees that are comprised of medical examiners,
22 coroners, death scene investigators, law enforcement
23 personnel, or emergency medical technicians and
24 paramedics, integrate training under the grant on

1 death scene investigation of SUID and SUDC into
2 professional accreditation and training programs;

3 “(5) in the case of State and local government
4 entity grantees, obtain equipment, including com-
5 puter equipment, to aid in the completion of stand-
6 ard death scene investigation; or

7 “(6) conduct training activities for medical ex-
8 aminers, coroners, and forensic pathologists con-
9 cerning standard autopsy protocols for sudden unex-
10 pected infant death and sudden unexplained death in
11 childhood and integrate the training under the grant
12 on standard autopsy protocols in SUID and SUDC
13 into professional accreditation and training pro-
14 grams.

15 “(d) AUTHORIZATION OF APPROPRIATIONS.—There
16 is authorized to be appropriated to carry out this section
17 \$2,000,000 for each of fiscal years 2017 through 2021.

18 **“SEC. 39900-3. INFANT AND CHILD DEATH REVIEW.**

19 “(a) PREVENTION.—

20 “(1) CORE CAPACITY GRANTS.—The Secretary,
21 acting through the Administrator, shall award
22 grants to States to build and strengthen State ca-
23 pacity and implement State and local infant and
24 child death review programs and prevention strate-
25 gies.

1 “(2) PLANNING GRANTS.—The Secretary, act-
2 ing through the Administrator, shall award planning
3 grants to States that have no existing infant or child
4 death review program or States in which the only in-
5 fant and child death review programs are State-
6 based, for the development of local infant and child
7 death review programs and prevention strategies.

8 “(3) APPLICATION.—To be eligible to receive a
9 grant under paragraph (1) or (2), a State shall sub-
10 mit to the Secretary an application at such time, in
11 such manner, and containing such information as
12 the Secretary may require.

13 “(4) TECHNICAL ASSISTANCE.—The Secretary,
14 acting through the Administrator, shall provide tech-
15 nical assistance to assist States—

16 “(A) in developing the capacity for com-
17 prehensive infant and child death review pro-
18 grams, including the development of best prac-
19 tices for the implementation of such programs;
20 and

21 “(B) in maintaining the national infant
22 and child death case reporting system.

23 “(b) AUTHORIZATION OF APPROPRIATIONS.—There
24 is authorized to be appropriated \$7,000,000 for each of

1 fiscal years 2017 through 2021 to carry out subsection
2 (a).

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

4 “(a) IN GENERAL.—The Secretary, acting through
5 the Administrator, shall award grants to national organi-
6 zations, State and local health departments, community-
7 based organizations, and nonprofit organizations for the
8 provisions of support services to families who have had
9 a child die of sudden unexpected infant death and sudden
10 unexplained death in childhood.

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

15 “(c) USE OF FUNDS.—Amounts received under a
16 grant awarded under subsection (a) may be used to pro-
17 vide grief counseling, education, home visits, 24-hour hot-
18 lines, ensure access to grief and bereavement services,
19 build capacity in professionals working with families who
20 experience a sudden death, and support groups for fami-
21 lies who have lost a child to sudden unexpected infant
22 death or sudden unexplained death in childhood.

23 “(d) PREFERENCE.—In awarding grants under sub-
24 section (a), the Secretary shall give preference to commu-
25 nity-based applicants that have a proven history of effec-

1 tive direct support services and interventions for sudden
2 unexpected infant death and sudden unexplained death in
3 childhood and can demonstrate experience through col-
4 laborations and partnerships for delivering services
5 throughout a State or region.

6 “(e) AUTHORIZATION OF APPROPRIATIONS.—There
7 is authorized to be appropriated to carry out this section
8 \$1,000,000 for each of fiscal years 2017 through 2021.

9 **“SEC. 39900-5. EVALUATION OF STATE AND REGIONAL**
10 **NEEDS.**

11 “(a) IN GENERAL.—The Secretary, acting through
12 the Director and in consultation with the Administrator,
13 shall conduct a needs assessment on a State and regional
14 basis of the availability of personnel, training, technical
15 assistance, and resources for investigating and deter-
16 mining sudden unexpected infant death and sudden unex-
17 plained death in childhood and make recommendations to
18 increase collaboration on a State and regional level for in-
19 vestigation and determination.

20 “(b) AUTHORIZATION OF APPROPRIATIONS.—There
21 is authorized to be appropriated to carry out this section
22 \$250,000 for each of fiscal years 2017 through 2021.”.

1 **SEC. 4. ENHANCING PUBLIC HEALTH ACTIVITIES RELATED**
2 **TO STILLBIRTH.**

3 Part P of title III of the Public Health Service Act
4 (42 U.S.C. 280g et seq.) is amended by adding at the end
5 the following:

6 **“SEC. 399V-6. ENHANCING PUBLIC HEALTH ACTIVITIES RE-**
7 **LATED TO STILLBIRTH.**

8 “(a) GRANTS.—The Secretary, acting through the
9 Director of the Centers for Disease Control and Preven-
10 tion, shall award grants to eligible States to enhance and
11 expand surveillance efforts to collect thorough and com-
12 plete epidemiologic information on stillbirths, including
13 through the utilization of the infrastructure of existing
14 surveillance systems (including vital statistics systems).

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

17 “(1) be a State; and

18 “(2) submit to the Secretary an application at
19 such time, in such manner, and containing such in-
20 formation as the Secretary may require, including—

21 “(A) an assurance that the applicant will
22 implement the standardized surveillance pro-
23 tocol developed under subsection (c); and

24 “(B) a description of the infrastructure of
25 existing surveillance systems in the State.

1 “(c) SURVEILLANCE PROTOCOL.—The Secretary,
2 acting through the Director of the Centers for Disease
3 Control and Prevention, shall—

4 “(1) provide for the continued development and
5 dissemination of a standard protocol for stillbirth
6 data collection and surveillance, in consultation with
7 representatives of health and advocacy organizations,
8 State and local governments, and other interested
9 entities determined appropriate by the Secretary;

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

15 “(3) develop and evaluate methods to link exist-
16 ing data to provide more complete information for
17 research into the causes and conditions associated
18 with stillbirth.

19 “(d) POSTMORTEM EVALUATION AND DATA COLLEC-
20 TION.—The Secretary, acting through the Director of the
21 Centers for Disease Control and Prevention and in con-
22 sultation with physicians, nurses, pathologists, geneticists,
23 parents, and other groups determined necessary by the Di-
24 rector, shall develop guidelines for increasing the perform-
25 ance and data collection of postmortem stillbirth evalua-

1 tion, including conducting and reimbursing autopsies, pla-
2 cental histopathology, and cytogenetic testing. The guide-
3 lines should take into account cultural competency issues
4 related to postmortem stillbirth evaluation.

5 “(e) PUBLIC HEALTH PROGRAMMATIC ACTIVITIES
6 RELATED TO STILLBIRTH.—The Secretary, acting
7 through the Director of the Centers for Disease Control
8 and Prevention, shall—

9 “(1) develop behavioral surveys for women ex-
10 perienceing stillbirth, using existing State-based in-
11 frastructure for pregnancy-related information gath-
12 ering;

13 “(2) increase the technical assistance provided
14 to States, Indian tribes, territories, and local com-
15 munities to enhance capacity for improved investiga-
16 tion of medical and social factors surrounding still-
17 birth events; and

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

21 “(f) PUBLIC EDUCATION AND PREVENTION PRO-
22 GRAMS.—The Secretary, acting through the Director of
23 the Centers for Disease Control and Prevention and in
24 consultation with health care providers, public health or-
25 ganizations, maternal and child health programs, parents,

1 and other groups deemed necessary by the Director, shall
2 directly or through grants, cooperative agreements, or con-
3 tracts to eligible entities, develop and conduct evidence-
4 based public education and prevention programs aimed at
5 reducing the occurrence of stillbirth overall and addressing
6 the racial and ethnic disparities in its occurrence, includ-
7 ing—

8 “(1) public education programs, services, and
9 demonstrations which are designed to increase gen-
10 eral awareness of stillbirths; and

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

17 “(g) TASK FORCE.—The Secretary, in consultation
18 with the Director of the National Institutes of Health, the
19 Director of the Centers for Disease Control and Preven-
20 tion, and health care providers, researchers, parents, and
21 other groups deemed necessary by the Directors, shall es-
22 tablish a task force to develop a national research plan
23 to determine the causes of, and how to prevent, stillbirth.

24 “(h) GRANTS FOR SUPPORT SERVICES.—

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

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

13 “(3) USE OF FUNDS.—Amounts received under
14 a grant awarded under paragraph (1) may be used
15 to provide grief counseling, education, home visits,
16 24-hour hotlines, ensure access to grief and bereave-
17 ment services, build capacity in professionals work-
18 ing with families who experience a sudden death,
19 and support groups for families who have experi-
20 enced stillbirth.

21 “(4) PREFERENCE.—In awarding grants under
22 paragraph (1), the Secretary shall give preference to
23 applicants that are community-based organizations
24 that have a proven history of providing effective di-
25 rect support services and interventions related to

1 stillbirths and can demonstrate experience through
2 collaborations and partnerships for delivering serv-
3 ices throughout a State or region.

4 “(i) DEFINITIONS.—In this section:

5 “(1) The term ‘State’ has the meaning given to
6 such term in section 2, except that such term in-
7 cludes tribes and tribal organizations (as such terms
8 are defined in section 4 of the Indian Self-Deter-
9 mination and Education Assistance Act).

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

14 “(j) AUTHORIZATION OF APPROPRIATIONS.—There
15 is authorized to be appropriated to carry out this section
16 \$3,000,000 for each of fiscal years 2017 through 2021.”.

○