

113TH CONGRESS
1ST SESSION

S. 314

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

FEBRUARY 13, 2013

Mr. LAUTENBERG introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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 “Sudden Unexpected
5 Death Data Enhancement and Awareness Act”.

1 **SEC. 2. AMENDMENT TO THE PUBLIC HEALTH SERVICE**
 2 **ACT.**

3 Title III of the Public Health Service Act (42 U.S.C.
 4 241 et seq.) is amended by adding at the end the fol-
 5 lowing:

6 **“PART W—SUDDEN UNEXPECTED INFANT DEATH**
 7 **AND SUDDEN UNEXPLAINED DEATH IN**
 8 **CHILDHOOD**

9 **“SEC. 39900. DEFINITIONS.**

10 “In this part:

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

14 “(2) DEATH SCENE INVESTIGATOR.—The term
 15 ‘death scene investigator’ means an individual cer-
 16 tified as a death scene investigator by an accredited
 17 professional certification board.

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

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

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

8 “(6) SUDDEN UNEXPLAINED DEATH IN CHILD-
 9 HOOD; SUDC.—The terms ‘sudden unexplained death
 10 in childhood’ and ‘SUDC’ mean the sudden death of
 11 a child older than 1 year of age which remains unex-
 12 plained after a thorough case investigation that in-
 13 cludes a review of the clinical history and cir-
 14 cumstances of death and performance of a complete
 15 autopsy with appropriate ancillary testing.

16 **“SEC. 39900-1. DEATH SCENE INVESTIGATION AND AU-**
 17 **TOPSY.**

18 “(a) INVESTIGATIONS.—

19 “(1) GRANTS.—The Secretary, acting through
 20 the Director, shall award grants to States to enable
 21 such States to improve the completion of comprehen-
 22 sive death scene investigations for sudden unex-
 23 pected infant death and sudden unexplained death in
 24 childhood.

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

6 “(3) USE OF FUNDS.—

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

19 “(B) PROTOCOLS.—A standard death
20 scene protocol implemented under subparagraph
21 (A) shall include the obtaining of information
22 on current and past medical history of the in-
23 fant/child, the circumstances surrounding the
24 death including any suspicious circumstances,
25 the sleep position and sleep environment of the

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

12 “(b) AUTOPSIES.—

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

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

24 “(3) COMPREHENSIVE AUTOPSY.—For purposes
25 of this subsection, a comprehensive autopsy shall in-

1 include a full external and internal examination, in-
2 cluding microscopic examination, of all major organs
3 and tissues including the brain, complete radio-
4 graphs, vitreous fluid analysis, photo documentation,
5 selected microbiology when indicated, metabolic test-
6 ing, and toxicology screening of the infant or child
7 involved.

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

1 “(c) STUDY ON GENETIC TESTING.—The Director,
 2 in consultation with medical examiners, coroners, forensic
 3 pathologists, geneticists, researchers, public health offi-
 4 cials, and other individuals and groups determined nec-
 5 essary by the Director, shall commission a study to deter-
 6 mine the benefits and appropriateness of genetic testing
 7 for infant and early childhood deaths that remain unex-
 8 plained after a complete death scene investigation and
 9 comprehensive, standardized autopsy. Such study shall in-
 10 clude recommendations on developing a standard protocol
 11 for use in determining when to utilize genetic testing and
 12 standard protocols for the collection and storage of speci-
 13 mens suitable for genetic testing.

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

17 **“SEC. 39900-2. TRAINING.**

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

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

24 “(1) be—

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

1 “(B) a nonprofit private entity; and

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

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

7 “(1) provide training to medical examiners,
8 coroners, death scene investigators, law enforcement
9 personnel, and emergency medical technicians or
10 paramedics concerning death scene investigations for
11 SUID and SUDC, including the use of standard
12 death scene investigation protocols that include in-
13 formation on the current and past medical history of
14 the infant/child, the circumstances surrounding the
15 death including any suspicious circumstances, the
16 sleep position and sleep environment of the infant/
17 child, and whether there were any accidental or envi-
18 ronmental factors associated with the death;

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

23 “(3) provide training to multidisciplinary teams,
24 including teams that have a medical examiner or
25 coroner, death scene investigator, law enforcement

1 representative, and an emergency medical technician
2 or paramedic;

3 “(4) in the case of national and State-based
4 grantees that are comprised of medical examiners,
5 coroners, death scene investigators, law enforcement
6 personnel, or emergency medical technicians and
7 paramedics, integrate training under the grant on
8 death scene investigation of SUID and SUDC into
9 professional accreditation and training programs;

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

14 “(6) conduct training activities for medical ex-
15 aminers, coroners, and forensic pathologists con-
16 cerning standard autopsy protocols for sudden unex-
17 pected infant death and sudden unexplained death in
18 childhood and integrate the training under the grant
19 on standard autopsy protocols in SUID and SUDC
20 into professional accreditation and training pro-
21 grams.

22 “(d) AUTHORIZATION OF APPROPRIATIONS.—There
23 is authorized to be appropriated to carry out this section
24 \$2,000,000 for each of fiscal years 2014 through 2018.

1 **“SEC. 39900–3. CHILD DEATH REVIEW.**

2 “(a) PREVENTION.—

3 “(1) CORE CAPACITY GRANTS.—The Secretary,
4 acting through the Administrator, shall award
5 grants to States to build and strengthen State ca-
6 pacity and implement State and local child death re-
7 view programs and prevention strategies.

8 “(2) PLANNING GRANTS.—The Secretary, act-
9 ing through the Administrator, shall award planning
10 grants to States that have no existing child death re-
11 view program or States in which the only child death
12 review programs are State-based, for the develop-
13 ment of local child death review programs and pre-
14 vention strategies.

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

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

23 “(A) in developing the capacity for com-
24 prehensive child death review programs, includ-
25 ing the development of best practices for the
26 implementation of such programs; and

1 “(B) in maintaining the national child
2 death case reporting system.

3 “(b) AUTHORIZATION OF APPROPRIATIONS.—There
4 is authorized to be appropriated \$7,000,000 for each of
5 fiscal years 2014 through 2018 to carry out subsection
6 (a).

7 **“SEC. 39900–4. ENHANCING THE NATIONAL CHILD DEATH**
8 **CASE REPORTING SYSTEM.**

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

20 “(b) GOALS OF MODIFIED NATIONAL CHILD DEATH
21 CASE REPORTING SYSTEM.—The modifications under
22 subsection (a) to the national child death case reporting
23 system shall facilitate the collection, analysis, and dissemi-
24 nation of data by—

1 “(1) implementing a surveillance and moni-
2 toring system based on thorough and complete death
3 scene investigation data, clinical history, and au-
4 topsy findings;

5 “(2) collecting standardized information about
6 the environmental, medical, genetic, and social cir-
7 cumstances of death (including sleep environment
8 and quality of the death scene investigation) if de-
9 termined that such may correlate with infant and
10 early childhood deaths, as well as information from
11 other law enforcement, medical examiner, coroner,
12 emergency medical services (EMS), medical records,
13 and vital records (if possible);

14 “(3) supporting multidisciplinary infant and
15 early childhood death reviews such as those per-
16 formed by child death review committees to collect
17 and review the standardized information and accu-
18 rately and consistently classify and characterize
19 SUID and SUDC;

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

24 “(5) utilizing current infrastructure of existing
25 surveillance systems.

1 “(c) AUTHORIZATION OF APPROPRIATIONS.—There
 2 is authorized to be appropriated to carry out this section
 3 \$3,000,000 for each of fiscal years 2014 through 2018.

4 **“SEC. 39900–5. PUBLIC AWARENESS AND EDUCATION CAM-**
 5 **PAIGN.**

6 “(a) ESTABLISHMENT.—The Secretary, acting
 7 through the Administrator and in consultation with the
 8 Director and the Director of the National Institutes of
 9 Health, shall establish and implement a culturally com-
 10 petent research-based public health awareness and edu-
 11 cation campaign to provide information that is focused on
 12 decreasing the risk factors that contribute to sudden unex-
 13 pected infant death and sudden unexplained death in
 14 childhood, including educating individuals and organiza-
 15 tions about safe sleep environments, sleep positions, and
 16 reducing exposure to smoking during pregnancy and after
 17 birth.

18 “(b) TARGETED POPULATIONS.—The campaign
 19 under subsection (a) shall be designed to reduce health
 20 disparities through the targeting of populations with high
 21 rates of sudden unexpected infant death and sudden unex-
 22 plained death in childhood.

23 “(c) CONSULTATION.—In establishing and imple-
 24 menting the campaign under subsection (a), the Secretary
 25 shall consult with national organizations representing

1 health care providers, including nurses and physicians,
2 parents, child care providers, children’s advocacy and safe-
3 ty organizations, maternal and child health programs and
4 women’s, infants’, and children’s nutrition professionals,
5 and other individuals and groups determined necessary by
6 the Secretary for such establishment and implementation.

7 “(d) GRANTS.—

8 “(1) IN GENERAL.—In carrying out the cam-
9 paign under subsection (a), the Secretary shall
10 award grants to national organizations, State and
11 local health departments, and community-based or-
12 ganizations for the conduct of education and out-
13 reach programs for health care providers, parents,
14 child care providers, public health agencies, and
15 community organizations.

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

21 “(e) AUTHORIZATION OF APPROPRIATIONS.—There
22 is authorized to be appropriated to carry out this section
23 \$7,000,000 for fiscal year 2014 and \$5,000,000 for each
24 of fiscal years 2015 through 2018.

1 **“SEC. 39900–6. GRANTS FOR SUPPORT SERVICES.**

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

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

13 “(c) USE OF FUNDS.—Amounts received under a
14 grant awarded under subsection (a) may be used to pro-
15 vide grief counseling, education, home visits, 24-hour hot-
16 lines, and support groups for families who have lost a child
17 to sudden unexpected infant death or sudden unexplained
18 death in childhood.

19 “(d) PREFERENCE.—In awarding grants under sub-
20 section (a), the Secretary shall give preference to commu-
21 nity-based applicants that have a proven history of effec-
22 tive direct support services and interventions for sudden
23 unexpected infant death and sudden unexplained death in
24 childhood and can demonstrate experience through col-
25 laborations and partnerships for delivering services
26 throughout a State or region.

1 “(e) AUTHORIZATION OF APPROPRIATIONS.—There
 2 is authorized to be appropriated to carry out this section
 3 \$500,000 for each of fiscal years 2014 through 2018.

4 **“SEC. 39900-7. EVALUATION OF STATE AND REGIONAL**
 5 **NEEDS.**

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

15 “(b) AUTHORIZATION OF APPROPRIATIONS.—There
 16 is authorized to be appropriated to carry out this section,
 17 \$250,000 for each of fiscal years 2014 through 2018.”.

18 **SEC. 3. ENHANCING PUBLIC HEALTH ACTIVITIES RELATED**
 19 **TO STILLBIRTH.**

20 Part P of title III of the Public Health Service Act
 21 (42 U.S.C. 280g et seq.) is amended by adding at the end
 22 the following:

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

3 “(a) GRANTS.—The Secretary, acting through the
 4 Director of the Centers for Disease Control and Preven-
 5 tion, shall award grants to eligible States and metropolitan
 6 areas to enhance and expand surveillance efforts to collect
 7 thorough and complete epidemiologic information on still-
 8 births, including through the utilization of the infrastruc-
 9 ture of existing surveillance systems (including vital statis-
 10 tics systems).

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

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

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

18 “(A) an assurance that the applicant will
 19 implement the standardized surveillance pro-
 20 tocol developed under subsection (c); and

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

24 “(c) SURVEILLANCE PROTOCOL.—The Secretary,
 25 acting through the Director of the Centers for Disease
 26 Control and Prevention, shall—

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

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

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

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

1 lines should take into account cultural competency issues
 2 related to postmortem stillbirth evaluation.

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

7 “(1) develop behavioral surveys for women ex-
 8 perienicing stillbirth, using existing State-based in-
 9 frastructure for pregnancy-related information gath-
 10 ering; and

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

16 “(f) PUBLIC EDUCATION AND PREVENTION PRO-
 17 GRAMS.—The Secretary, acting through the Director of
 18 the Centers for Disease Control and Prevention and in
 19 consultation with health care providers, public health or-
 20 ganizations, maternal and child health programs, parents,
 21 and other groups deemed necessary by the Director, shall
 22 directly or through grants, cooperative agreements, or con-
 23 tracts to eligible entities, develop and conduct evidence-
 24 based public education and prevention programs aimed at
 25 reducing the occurrence of stillbirth overall and addressing

1 the racial and ethnic disparities in its occurrence, includ-
 2 ing—

3 “(1) public education programs, services, and
 4 demonstrations which are designed to increase gen-
 5 eral awareness of stillbirths; and

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

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

19 “(h) GRANTS FOR SUPPORT SERVICES.—

20 “(1) IN GENERAL.—The Secretary, acting
 21 through the Administrator of the Health Resources
 22 and Services Administration, shall award grants to
 23 national organizations, State and local health de-
 24 partments, and community-based organizations, for

1 the provisions of support services to families who
2 have experienced stillbirth.

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

8 “(3) USE OF FUNDS.—Amounts received under
9 a grant awarded under subsection (a) may be used
10 to provide grief counseling, education, home visits,
11 24-hour hotlines, and support groups for families
12 who have experienced stillbirth.

13 “(4) PREFERENCE.—In awarding grants under
14 subsection (a), the Secretary shall give preference to
15 applicants that are community-based organizations
16 that have a proven history of providing effective di-
17 rect support services and interventions related to
18 stillbirths and can demonstrate experience through
19 collaborations and partnerships for delivering serv-
20 ices throughout a State or region.

21 “(i) DEFINITIONS.—In this section:

22 “(1) The term ‘State’ has the meaning given to
23 such term in section 2, except that such term in-
24 cludes tribes and tribal organizations (as such terms

1 are defined in section 4 of the Indian Self-Deter-
2 mination and Education Assistance Act).

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

7 “(j) AUTHORIZATION OF APPROPRIATIONS.—There
8 is authorized to be appropriated to carry out this section,
9 \$3,000,000 for each of fiscal years 2014 through 2018.”.

10 **SEC. 4. REPORT TO CONGRESS.**

11 Not later than 2 years after the date of enactment
12 of this Act, the Secretary of Health and Human Services,
13 acting through the Director of the Centers for Disease
14 Control and Prevention and in consultation with the Di-
15 rector of the National Institutes of Health and the Admin-
16 istrator of the Health Resources and Services Administra-
17 tion, shall submit to Congress a report describing the
18 progress made in implementing this Act (and the amend-
19 ments made by this Act).

○