

Union Calendar No.

113TH CONGRESS
2^D SESSION

H. R. 669

[Report No. 113-]

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

JULY --, 2014

Reported with an amendment, committed to the Committee of the Whole House on the State of the Union, and ordered to be printed

[Strike out all after the enacting clause and insert the part printed in *italic*]

[For text of introduced bill, see copy of bill as introduced on February 13, 2013]

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”.*

6 **SEC. 2. STILLBIRTH AND SUDDEN DEATHS IN THE YOUNG.**

7 *The Public Health Service Act is amended by inserting*
8 *after section 317L of such Act (42 U.S.C. 247b–13) the fol-*
9 *lowing:*

10 **“SEC. 317L–1. STILLBIRTH AND SUDDEN DEATHS IN THE**
11 **YOUNG.**

12 “(a) *STILLBIRTH ACTIVITIES.—The Secretary, acting*
13 *through the Director of the Centers for Disease Control and*
14 *Prevention, shall continue to carry out activities of the Cen-*
15 *ters relating to stillbirth, including the following:*

16 “(1) *SURVEILLANCE.—*

17 “(A) *IN GENERAL.—The Secretary shall*
18 *provide for surveillance efforts to collect thor-*
19 *ough, complete, and high-quality epidemiologic*
20 *information on stillbirths, including through the*
21 *utilization of existing surveillance systems (in-*
22 *cluding the National Vital Statistics System*
23 *(NVSS) and other appropriately equipped birth*
24 *defects surveillance programs).*

1 “(B) *STANDARD PROTOCOL FOR SURVEIL-*
2 *LANCE.—The Secretary, in consultation with*
3 *qualified individuals and organizations deter-*
4 *mined appropriate by the Secretary, to include*
5 *representatives of health and advocacy organiza-*
6 *tions, State and local governments, public health*
7 *officials, and health researchers, shall—*

8 “(i) *provide for the continued develop-*
9 *ment and dissemination of a standard pro-*
10 *tol for stillbirth data collection and sur-*
11 *veillance; and*

12 “(ii) *not less than every 5 years, re-*
13 *view and, as appropriate, update such pro-*
14 *tol.*

15 “(2) *POSTMORTEM DATA COLLECTION AND EVAL-*
16 *UATION.—The Secretary, in consultation with quali-*
17 *fied individuals and organizations determined appro-*
18 *priate by the Secretary, to include representatives of*
19 *health professional organizations, shall—*

20 “(A) *upon the enactment of this section,*
21 *and not less than every 5 years thereafter, review*
22 *existing guidelines for increasing and improving*
23 *the quality and completeness of postmortem still-*
24 *birth evaluation and related data collection, in-*
25 *cluding conducting and reimbursing autopsies,*

1 *placental histopathology, and cytogenetic testing;*
2 *and*

3 *“(B) develop strategies for implementing*
4 *such guidelines and addressing any barriers to*
5 *implementation of such guidelines.*

6 *“(b) SUDDEN UNEXPECTED INFANT DEATH ACTIVI-*
7 *TIES.—The Secretary, acting through the Director of the*
8 *Centers for Disease Control and Prevention, shall continue*
9 *to carry out activities of the Centers relating to sudden un-*
10 *expected infant death (SUID), including the following:*

11 *“(1) SURVEILLANCE.—*

12 *“(A) IN GENERAL.—The Secretary shall*
13 *provide for surveillance efforts to gather*
14 *sociodemographic, death scene investigation, clin-*
15 *ical history, and autopsy information on SUID*
16 *cases through the review of existing records on*
17 *SUID, including through the utilization of exist-*
18 *ing surveillance systems (including the national*
19 *child death review case reporting system and*
20 *SUID case registries).*

21 *“(B) STANDARD PROTOCOL FOR SURVEIL-*
22 *LANCE.—The Secretary, in consultation with*
23 *qualified individuals and organizations deter-*
24 *mined appropriate by the Secretary, to include*
25 *representatives of health and advocacy organiza-*

1 *tions, State and local governments, and public*
2 *health officials, shall—*

3 *“(i) provide for the continued develop-*
4 *ment and dissemination of a standard pro-*
5 *tol for SUID data reporting and surveil-*
6 *lance; and*

7 *“(ii) not less than every 5 years, re-*
8 *view and, as appropriate, update such pro-*
9 *tol.*

10 *“(C) GOALS FOR ENHANCING SURVEIL-*
11 *LANCE.—In carrying out activities under this*
12 *subsection, the Secretary shall seek to accomplish*
13 *the following goals:*

14 *“(i) Collecting thorough, complete, and*
15 *high-quality death scene investigation data,*
16 *clinical history, and autopsy findings.*

17 *“(ii) Collecting standardized informa-*
18 *tion about the environmental and medical*
19 *circumstances of death (including the sleep*
20 *environment and quality of the death scene*
21 *investigation).*

22 *“(iii) Supporting multidisciplinary*
23 *infant death reviews, such as those per-*
24 *formed by child death review committees, to*
25 *collect and review the information and clas-*

1 *sify and characterize SUID using a stand-*
2 *ardized classification system.*

3 “(iv) *Facilitating the sharing of infor-*
4 *mation to improve the public reporting of*
5 *surveillance and vital statistics describing*
6 *the epidemiology of SUID.*

7 “(2) *STANDARD PROTOCOL FOR DEATH SCENE*
8 *INVESTIGATION.—*

9 “(A) *IN GENERAL.—The Secretary, in con-*
10 *sultation with forensic pathologists, medical ex-*
11 *aminers, coroners, medicolegal death scene inves-*
12 *tigators, law enforcement personnel, emergency*
13 *medical technicians and paramedics, public*
14 *health agencies, and other individuals and orga-*
15 *nizations determined appropriate by the Sec-*
16 *retary, shall—*

17 “(i) *provide for the continued dissemi-*
18 *nation of a standard death scene investiga-*
19 *tion protocol; and*

20 “(ii) *not less than every 5 years, re-*
21 *view and, as appropriate, update such pro-*
22 *tol.*

23 “(B) *CONTENT OF DEATH SCENE PRO-*
24 *TOCOL.—The protocol disseminated under sub-*
25 *paragraph (A) shall include information on—*

1 “(i) *the current and past medical his-*
2 *tory of the infant;*

3 “(ii) *family medical history;*

4 “(iii) *the circumstances surrounding*
5 *the death, including any suspicious cir-*
6 *cumstances;*

7 “(iv) *the sleep position and sleep envi-*
8 *ronment of the infant; and*

9 “(v) *any accidental or environmental*
10 *factors associated with death.*

11 “(3) *GUIDELINES FOR A STANDARD AUTOPSY*
12 *PROTOCOL.—The Secretary, in consultation with the*
13 *Attorney General of the United States, forensic pa-*
14 *thologists, medical examiners, coroners, pediatric pa-*
15 *thologists, pediatric cardiologists, pediatric*
16 *neuropathologists, geneticists, infectious disease spe-*
17 *cialists, and other individuals and organizations de-*
18 *termined appropriate by the Secretary, shall—*

19 “(A) *develop guidelines for a standard au-*
20 *topsy protocol for SUID; and*

21 “(C) *not less than every 5 years, review*
22 *and, as appropriate, update such guidelines.*

23 “(4) *TRAINING.—The Secretary, in consultation*
24 *with the Attorney General of the United States,*
25 *may—*

1 “(A) *conduct or support—*

2 “(i) *training activities for medical ex-*
3 *aminers, coroners, medicolegal death scene*
4 *investigators, law enforcement personnel,*
5 *and emergency medical technicians or para-*
6 *medics concerning death scene investiga-*
7 *tions for SUID, including the use of stand-*
8 *ard death scene investigation protocols dis-*
9 *seminated under paragraph (2); and*

10 “(ii) *training activities for medical ex-*
11 *aminers, coroners, and forensic pathologists*
12 *concerning standard autopsy protocols for*
13 *SUID developed under paragraph (3); and*

14 “(B) *make recommendations to health pro-*
15 *fessional organizations regarding the integration*
16 *of protocols disseminated or developed under this*
17 *subsection, and training conducted or supported*
18 *under this paragraph, into existing training and*
19 *continuing education programs.*

20 “(c) *SUDDEN UNEXPLAINED DEATH IN CHILDHOOD*
21 *ACTIVITIES.—The Secretary, acting through the Director of*
22 *the Centers for Disease Control and Prevention, shall con-*
23 *tinue to carry out activities of the Centers relating to sud-*
24 *den unexpected death in childhood (SUDC), including the*
25 *following:*

1 “(1) *SURVEILLANCE.*—*The Secretary, in con-*
2 *sultation with the Director of the National Institutes*
3 *of Health, shall provide for surveillance efforts to*
4 *gather sociodemographic, death scene investigation,*
5 *clinical history, and autopsy information on SUDC*
6 *cases through the review of existing records on SUDC,*
7 *including through the utilization of existing surveil-*
8 *lance systems (including the Sudden Death in the*
9 *Young Registry).*

10 “(2) *GUIDELINES FOR A STANDARD AUTOPSY*
11 *PROTOCOL.*—*The Secretary, in consultation with the*
12 *Attorney General of the United States, forensic pa-*
13 *thologists, medical examiners, coroners, pediatric pa-*
14 *thologists, pediatric cardiologists, pediatric*
15 *neuropathologists, geneticists, infectious disease spe-*
16 *cialists, and other individuals and organizations de-*
17 *termined appropriate by the Secretary, may—*

18 “(A) *develop guidelines for a standard au-*
19 *topsy protocol for SUDC; and*

20 “(B) *not less than every 5 years, review*
21 *and, as appropriate, update such guidelines.*

22 “(3) *REVIEW OF APPLICABILITY OF PROGRAMS*
23 *AND ACTIVITIES.*—*Not later than 18 months after the*
24 *date of enactment of this section, the Secretary, acting*
25 *through the Director of the Centers for Disease Con-*

1 *trol and Prevention, and in consultation with the Di-*
2 *rector of the National Institutes of Health, shall com-*
3 *plete an evaluation of the possibility of carrying out*
4 *or intensifying, with respect to SUDC, the types of*
5 *programs and activities that are authorized to be car-*
6 *ried out under subsection (b) with respect to SUID.*

7 *“(d) REPORT TO CONGRESS.—Not later than 2 years*
8 *after the date of enactment of this Act, the Secretary, acting*
9 *through the Director of the Centers for Disease Control and*
10 *Prevention, shall submit to the Congress a report on the*
11 *implementation of this section. Such report shall include—*

12 *“(1) the results of the evaluation under sub-*
13 *section (c)(3); and*

14 *“(2) a description of any activities that—*

15 *“(A) are being carried out by the Centers*
16 *for Disease Control and Prevention in consulta-*
17 *tion with the National Institutes of Health relat-*
18 *ing to stillbirth, SUID, or SUDC; and*

19 *“(B) are in addition to the activities being*
20 *carried out pursuant to this section.*

21 *“(e) DEFINITIONS.—In this section:*

22 *“(1) The term ‘stillbirth’ means a spontaneous*
23 *fetal death that—*

24 *“(A) occurs at 20 or more weeks gestation;*

25 *or*

1 “(B) if the age of the fetus is not known, in-
2 volves a fetus weighing 350 grams or more.

3 “(2) The terms ‘sudden unexpected infant death’
4 and ‘SUID’ mean the death of an infant less than 1
5 year of age—

6 “(A) which occurs suddenly and unexpect-
7 edly; and

8 “(B) whose cause—

9 “(i) is not immediately obvious prior
10 to investigation; and

11 “(ii) is either explained upon inves-
12 tigation or remains unexplained.

13 “(3) The terms ‘sudden unexplained death in
14 childhood’ and ‘SUDC’ mean the sudden death of a
15 child 1 year of age or older which remains unex-
16 plained after a thorough case investigation that in-
17 cludes—

18 “(A) a review of the clinical history and
19 circumstances of death; and

20 “(B) performance of a complete autopsy
21 with appropriate ancillary testing.

22 “(f) FUNDING.—This section shall not be construed to
23 increase the amount of appropriations that are authorized
24 to be appropriated for any fiscal year.”.