

## COMMITTEE PRINT

[SHOWING H.R. 669, AS FAVORABLY FORWARDED BY THE SUBCOMMITTEE  
ON HEALTH ON JUNE 20, 2014]

113TH CONGRESS  
1ST SESSION

# H. R. 669

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.

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### 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

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## 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. STILLBIRTH AND SUDDEN DEATHS IN THE YOUNG.**

2 The Public Health Service Act is amended by insert-  
3 ing after section 317L of such Act (42 U.S.C. 247b–13)  
4 the following:

5 **“SEC. 317L–1. STILLBIRTH AND SUDDEN DEATHS IN THE**  
6 **YOUNG.**

7 “(a) STILLBIRTH ACTIVITIES.—The Secretary, act-  
8 ing through the Director of the Centers for Disease Con-  
9 trol and Prevention, shall continue to carry out activities  
10 of the Centers relating to stillbirth, including the fol-  
11 lowing:

12 “(1) SURVEILLANCE.—

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

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 organi-

1 zations, State and local governments, public  
2 health officials, and health researchers, shall—

3 “(i) provide for the continued develop-  
4 ment and dissemination of a standard pro-  
5 tocol for stillbirth data collection and sur-  
6 veillance; and

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

10 “(2) POSTMORTEM DATA COLLECTION AND  
11 EVALUATION.—The Secretary, in consultation with  
12 qualified individuals and organizations determined  
13 appropriate by the Secretary, to include representa-  
14 tives of health professional organizations, shall—

15 “(A) upon the enactment of this section,  
16 and not less than every 5 years thereafter, re-  
17 view existing guidelines for increasing and im-  
18 proving the quality and completeness of post-  
19 mortem stillbirth evaluation and related data  
20 collection, including conducting and reimburs-  
21 ing autopsies, placental histopathology, and cy-  
22 togenetic testing; and

23 “(B) develop strategies for implementing  
24 such guidelines and addressing any barriers to  
25 implementation of such guidelines.

1           “(b) SUDDEN UNEXPECTED INFANT DEATH ACTIVI-  
2 TIES.—The Secretary, acting through the Director of the  
3 Centers for Disease Control and Prevention, shall continue  
4 to carry out activities of the Centers relating to sudden  
5 unexpected infant death (SUID), including the following:

6           “(1) SURVEILLANCE.—

7           “(A) IN GENERAL.—The Secretary shall  
8 provide for surveillance efforts to gather  
9 sociodemographic, death scene investigation,  
10 clinical history, and autopsy information on  
11 SUID cases through the review of existing  
12 records on SUID, including through the utiliza-  
13 tion of existing surveillance systems (including  
14 the national child death review case reporting  
15 system and SUID case registries).

16           “(B) STANDARD PROTOCOL FOR SURVEIL-  
17 LANCE.—The Secretary, in consultation with  
18 qualified individuals and organizations deter-  
19 mined appropriate by the Secretary, to include  
20 representatives of health and advocacy organi-  
21 zations, State and local governments, and pub-  
22 lic health officials, shall—

23           “(i) provide for the continued develop-  
24 ment and dissemination of a standard pro-

1            protocol for SUID data reporting and surveil-  
2            lance; and

3                    “(ii) not less than every 5 years, re-  
4            view and, as appropriate, update such pro-  
5            tocol.

6                    “(C) GOALS FOR ENHANCING SURVEIL-  
7            LANCE.—In carrying out activities under this  
8            subsection, the Secretary shall seek to accom-  
9            plish the following goals:

10                    “(i) Collecting thorough, complete,  
11            and high-quality death scene investigation  
12            data, clinical history, and autopsy findings.

13                    “(ii) Collecting standardized informa-  
14            tion about the environmental and medical  
15            circumstances of death (including the sleep  
16            environment and quality of the death scene  
17            investigation).

18                    “(iii) Supporting multidisciplinary in-  
19            fant death reviews, such as those per-  
20            formed by child death review committees,  
21            to collect and review the information and  
22            classify and characterize SUID using a  
23            standardized classification system.

24                    “(iv) Facilitating the sharing of infor-  
25            mation to improve the public reporting of

1 surveillance and vital statistics describing  
2 the epidemiology of SUID.

3 “(2) STANDARD PROTOCOL FOR DEATH SCENE  
4 INVESTIGATION.—

5 “(A) IN GENERAL.—The Secretary, in con-  
6 sultation with forensic pathologists, medical ex-  
7 aminers, coroners, medicolegal death scene in-  
8 vestigators, law enforcement personnel, emer-  
9 gency medical technicians and paramedics, pub-  
10 lic health agencies, and other individuals and  
11 organizations determined appropriate by the  
12 Secretary, shall—

13 “(i) provide for the continued dissemi-  
14 nation of a standard death scene investiga-  
15 tion protocol; and

16 “(ii) not less than every 5 years, re-  
17 view and, as appropriate, update such pro-  
18 tocol.

19 “(B) CONTENT OF DEATH SCENE PRO-  
20 TOCOL.—The protocol disseminated under sub-  
21 paragraph (A) shall include information on—

22 “(i) the current and past medical his-  
23 tory of the infant;

24 “(ii) family medical history;

1 “(iii) the circumstances surrounding  
2 the death, including any suspicious cir-  
3 cumstances;

4 “(iv) the sleep position and sleep envi-  
5 ronment of the infant; and

6 “(v) any accidental or environmental  
7 factors associated with death.

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

16 “(A) develop guidelines for a standard au-  
17 topsy protocol for SUID; and

18 “(C) not less than every 5 years, review  
19 and, as appropriate, update such guidelines.

20 “(4) TRAINING.—The Secretary, in consultation  
21 with the Attorney General of the United States,  
22 may—

23 “(A) conduct or support—

24 “(i) training activities for medical ex-  
25 aminers, coroners, medicolegal death scene

1 investigators, law enforcement personnel,  
2 and emergency medical technicians or  
3 paramedics concerning death scene inves-  
4 tigations for SUID, including the use of  
5 standard death scene investigation proto-  
6 cols disseminated under paragraph (2);  
7 and

8 “(ii) training activities for medical ex-  
9 aminers, coroners, and forensic patholo-  
10 gists concerning standard autopsy proto-  
11 cols for SUID developed under paragraph  
12 (3); and

13 “(B) make recommendations to health pro-  
14 fessional organizations regarding the integra-  
15 tion of protocols disseminated or developed  
16 under this subsection, and training conducted  
17 or supported under this paragraph, into exist-  
18 ing training and continuing education pro-  
19 grams.

20 “(c) SUDDEN UNEXPLAINED DEATH IN CHILDHOOD  
21 ACTIVITIES.—The Secretary, acting through the Director  
22 of the Centers for Disease Control and Prevention, shall  
23 continue to carry out activities of the Centers relating to  
24 sudden unexpected death in childhood (SUDC), including  
25 the 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  
7           SUDC, including through the utilization of existing  
8           surveillance systems (including the Sudden Death in  
9           the 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  
24           the date of enactment of this section, the Secretary,  
25           acting through the Director of the Centers for Dis-

1 ease Control and Prevention, and in consultation  
2 with the Director of the National Institutes of  
3 Health, shall complete an evaluation of the possi-  
4 bility of carrying out or intensifying, with respect to  
5 SUDC, the types of programs and activities that are  
6 authorized to be carried out under subsection (b)  
7 with respect to SUID.

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

14 “(1) the results of the evaluation under sub-  
15 section (c)(3); and

16 “(2) a description of any activities that—

17 “(A) are being carried out by the Centers  
18 for Disease Control and Prevention in consulta-  
19 tion with the National Institutes of Health re-  
20 lating to stillbirth, SUID, or SUDC; and

21 “(B) are in addition to the activities being  
22 carried out pursuant to this section.

23 “(e) DEFINITIONS.—In this section:

24 “(1) The term ‘stillbirth’ means a spontaneous  
25 fetal death that—

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

2                   or

3                   “(B) if the age of the fetus is not known,

4                   involves a fetus weighing 350 grams or more.

5                   “(2) The terms ‘sudden unexpected infant

6                   death’ and ‘SUID’ mean the death of an infant less

7                   than 1 year of age—

8                   “(A) which occurs suddenly and unexpect-

9                   edly; and

10                  “(B) whose cause—

11                  “(i) is not immediately obvious prior

12                  to investigation; and

13                  “(ii) is either explained upon inves-

14                  tigation or remains unexplained.

15                  “(3) The terms ‘sudden unexplained death in

16                  childhood’ and ‘SUDC’ mean the sudden death of a

17                  child 1 year of age or older which remains unex-

18                  plained after a thorough case investigation that in-

19                  cludes—

20                  “(A) a review of the clinical history and

21                  circumstances of death; and

22                  “(B) performance of a complete autopsy

23                  with appropriate ancillary testing.

1       “(f) FUNDING.—This section shall not be construed  
2 to increase the amount of appropriations that are author-  
3 ized to be appropriated for any fiscal year.”.