

113TH CONGRESS  
2D SESSION

# H. R. 669

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IN THE SENATE OF THE UNITED STATES

SEPTEMBER 10, 2014

Received; read twice and referred to the Committee on Health, Education,  
Labor, and Pensions

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## AN ACT

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,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Sudden Unexpected  
3 Death Data Enhancement and Awareness Act”.

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

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

8 **“SEC. 317L–1. STILLBIRTH AND SUDDEN DEATHS IN THE**  
9 **YOUNG.**

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

15 “(1) SURVEILLANCE.—

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

24 “(B) STANDARD PROTOCOL FOR SURVEIL-  
25 LANCE.—The Secretary, in consultation with  
26 qualified individuals and organizations deter-

1           mined appropriate by the Secretary, to include  
2           representatives of health and advocacy organi-  
3           zations, State and local governments, public  
4           health officials, and health researchers, shall—

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

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

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

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

1           “(B) develop strategies for implementing  
2           such guidelines and addressing any barriers to  
3           implementation of such guidelines.

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

9           “(1) SURVEILLANCE.—

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

19           “(B) STANDARD PROTOCOL FOR SURVEILLANCE.—The Secretary, in consultation with  
20           qualified individuals and organizations determined appropriate by the Secretary, to include  
21           representatives of health and advocacy organizations, State and local governments, and public  
22           health officials, shall—  
23  
24  
25

1 “(i) provide for the continued develop-  
2 ment and dissemination of a standard pro-  
3 tocol for SUID data reporting and surveil-  
4 lance; and

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

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

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

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

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

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

5 “(2) STANDARD PROTOCOL FOR DEATH SCENE  
6 INVESTIGATION.—

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

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

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

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

24 “(i) the current and past medical his-  
25 tory of the infant;

1 “(ii) family medical history;

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

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

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

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

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

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

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

24 “(A) conduct or support—

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

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

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

22 “(c) SUDDEN UNEXPLAINED DEATH IN CHILDHOOD  
23 ACTIVITIES.—The Secretary, acting through the Director  
24 of the Centers for Disease Control and Prevention, shall  
25 continue to carry out activities of the Centers relating to



1 sudden unexpected death in childhood (SUDC), including  
2 the following:

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

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

20           “(A) develop guidelines for a standard au-  
21 topsy protocol for SUDC; and

22           “(B) not less than every 5 years, review  
23 and, as appropriate, update such guidelines.

24           “(3) REVIEW OF APPLICABILITY OF PROGRAMS  
25 AND ACTIVITIES.—Not later than 18 months after

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

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

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

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

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

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

25 “(e) DEFINITIONS.—In this section:

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

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

5                   “(B) if the age of the fetus is not known,  
6 involves a fetus weighing 350 grams or more.

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

10                   “(A) which occurs suddenly and unexpect-  
11 edly; and

12                   “(B) whose cause—

13                           “(i) is not immediately obvious prior  
14 to investigation; and

15                           “(ii) is either explained upon inves-  
16 tigation or remains unexplained.

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

22                   “(A) a review of the clinical history and  
23 circumstances of death; and

24                   “(B) performance of a complete autopsy  
25 with appropriate ancillary testing.

1       “(f) FUNDING.—No additional funds are authorized  
2 to be appropriated for the purpose of carrying out this  
3 section, and this section shall be carried out using  
4 amounts otherwise available for such purpose.”.

Passed the House of Representatives September 9,  
2014.

Attest:

KAREN L. HAAS,  
*Clerk.*