

113TH CONGRESS
2^D SESSION

H. R. 669

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 ACTIVI-
5 TIES.—The Secretary, acting through the Director of the
6 Centers for Disease Control and Prevention, shall continue
7 to carry out activities of the Centers relating to sudden
8 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 utiliza-
16 tion of existing surveillance systems (including
17 the national child death review case reporting
18 system and SUID case registries).

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

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:

Clerk.

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