

1 information on stillbirths, including through the
2 utilization of existing surveillance systems (in-
3 cluding the National Vital Statistics System
4 (NVSS) and other appropriately equipped birth
5 defects surveillance programs).

6 “(B) STANDARD PROTOCOL FOR SURVEIL-
7 LANCE.—The Secretary, in consultation with
8 qualified individuals and organizations deter-
9 mined appropriate by the Secretary, to include
10 representatives of health and advocacy organi-
11 zations, State and local governments, public
12 health officials, and health researchers, shall—

13 “(i) provide for the continued develop-
14 ment and dissemination of a standard pro-
15 tocol for stillbirth data collection and sur-
16 veillance; and

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

20 “(2) POSTMORTEM DATA COLLECTION AND
21 EVALUATION.—The Secretary, in consultation with
22 qualified individuals and organizations determined
23 appropriate by the Secretary, to include representa-
24 tives of health professional organizations, shall—

1 “(A) upon the enactment of this section,
2 and not less than every 5 years thereafter, re-
3 view existing guidelines for increasing and im-
4 proving the quality and completeness of post-
5 mortem stillbirth evaluation and related data
6 collection, including conducting and reimburs-
7 ing autopsies, placental histopathology, and cy-
8 togenetic testing; and

9 “(B) develop strategies for implementing
10 such guidelines and addressing any barriers to
11 implementation of such guidelines.

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

17 “(1) SURVEILLANCE.—

18 “(A) IN GENERAL.—The Secretary shall
19 provide for surveillance efforts to gather
20 sociodemographic, death scene investigation,
21 clinical history, and autopsy information on
22 SUID cases through the review of existing
23 records on SUID, including through the utiliza-
24 tion of existing surveillance systems (including

1 the national child death review case reporting
2 system and SUID case registries).

3 “(B) STANDARD PROTOCOL FOR SURVEIL-
4 LANCE.—The Secretary, in consultation with
5 qualified individuals and organizations deter-
6 mined appropriate by the Secretary, to include
7 representatives of health and advocacy organi-
8 zations, State and local governments, and pub-
9 lic health officials, shall—

10 “(i) provide for the continued develop-
11 ment and dissemination of a standard pro-
12 tocol for SUID data reporting and surveil-
13 lance; and

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

17 “(C) GOALS FOR ENHANCING SURVEIL-
18 LANCE.—In carrying out activities under this
19 subsection, the Secretary shall seek to accom-
20 plish the following goals:

21 “(i) Collecting thorough, complete,
22 and high-quality death scene investigation
23 data, clinical history, and autopsy findings.

24 “(ii) Collecting standardized informa-
25 tion about the environmental and medical

1 circumstances of death (including the sleep
2 environment and quality of the death scene
3 investigation).

4 “(iii) Supporting multidisciplinary in-
5 fant death reviews, such as those per-
6 formed by child death review committees,
7 to collect and review the information and
8 classify and characterize SUID using a
9 standardized classification system.

10 “(iv) Facilitating the sharing of infor-
11 mation to improve the public reporting of
12 surveillance and vital statistics describing
13 the epidemiology of SUID.

14 “(2) STANDARD PROTOCOL FOR DEATH SCENE
15 INVESTIGATION.—

16 “(A) IN GENERAL.—The Secretary, in con-
17 sultation with forensic pathologists, medical ex-
18 aminers, coroners, medicolegal death scene in-
19 vestigators, law enforcement personnel, emer-
20 gency medical technicians and paramedics, pub-
21 lic health agencies, and other individuals and
22 organizations determined appropriate by the
23 Secretary, shall—

1 “(i) provide for the continued dissemi-
2 nation of a standard death scene investiga-
3 tion protocol; and

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

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

10 “(i) the current and past medical his-
11 tory of the infant;

12 “(ii) family medical history;

13 “(iii) the circumstances surrounding
14 the death, including any suspicious cir-
15 cumstances;

16 “(iv) the sleep position and sleep envi-
17 ronment of the infant; and

18 “(v) any accidental or environmental
19 factors associated with death.

20 “(3) GUIDELINES FOR A STANDARD AUTOPSY
21 PROTOCOL.—The Secretary, in consultation with the
22 Attorney General of the United States, forensic pa-
23 thologists, medical examiners, coroners, pediatric pa-
24 thologists, pediatric cardiologists, pediatric
25 neuropathologists, geneticists, infectious disease spe-

1 cialists, and other individuals and organizations de-
2 termined appropriate by the Secretary, shall—

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

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

7 “(4) TRAINING.—The Secretary, in consultation
8 with the Attorney General of the United States,
9 may—

10 “(A) conduct or support—

11 “(i) training activities for medical ex-
12 aminers, coroners, medicolegal death scene
13 investigators, law enforcement personnel,
14 and emergency medical technicians or
15 paramedics concerning death scene inves-
16 tigation for SUID, including the use of
17 standard death scene investigation proto-
18 cols disseminated under paragraph (2);
19 and

20 “(ii) training activities for medical ex-
21 aminers, coroners, and forensic patholo-
22 gists concerning standard autopsy proto-
23 cols for SUID developed under paragraph
24 (3); and

1 “(B) make recommendations to health pro-
2 fessional organizations regarding the integra-
3 tion of protocols disseminated or developed
4 under this subsection, and training conducted
5 or supported under this paragraph, into exist-
6 ing training and continuing education pro-
7 grams.

8 “(c) SUDDEN UNEXPLAINED DEATH IN CHILDHOOD
9 ACTIVITIES.—The Secretary, acting through the Director
10 of the Centers for Disease Control and Prevention, shall
11 continue to carry out activities of the Centers relating to
12 sudden unexpected death in childhood (SUDC), including
13 the following:

14 “(1) SURVEILLANCE.—The Secretary, in con-
15 sultation with the Director of the National Institutes
16 of Health, shall provide for surveillance efforts to
17 gather sociodemographic, death scene investigation,
18 clinical history, and autopsy information on SUDC
19 cases through the review of existing records on
20 SUDC, including through the utilization of existing
21 surveillance systems (including the Sudden Death in
22 the Young Registry).

23 “(2) GUIDELINES FOR A STANDARD AUTOPSY
24 PROTOCOL.—The Secretary, in consultation with the
25 Attorney General of the United States, forensic pa-

1 pathologists, medical examiners, coroners, pediatric pa-
2 thologists, pediatric cardiologists, pediatric
3 neuropathologists, geneticists, infectious disease spe-
4 cialists, and other individuals and organizations de-
5 termined appropriate by the Secretary, may—

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

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

10 “(3) REVIEW OF APPLICABILITY OF PROGRAMS
11 AND ACTIVITIES.—Not later than 18 months after
12 the date of enactment of this section, the Secretary,
13 acting through the Director of the Centers for Dis-
14 ease Control and Prevention, and in consultation
15 with the Director of the National Institutes of
16 Health, shall complete an evaluation of the possi-
17 bility of carrying out or intensifying, with respect to
18 SUDC, the types of programs and activities that are
19 authorized to be carried out under subsection (b)
20 with respect to SUID.

21 “(d) REPORT TO CONGRESS.—Not later than 2 years
22 after the date of enactment of this Act, the Secretary, act-
23 ing through the Director of the Centers for Disease Con-
24 trol and Prevention, shall submit to the Congress a report

1 on the implementation of this section. Such report shall
2 include—

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

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

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

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

12 “(e) DEFINITIONS.—In this section:

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

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

16 or

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

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

22 “(A) which occurs suddenly and unexpect-
23 edly; and

24 “(B) whose cause—

1 “(i) is not immediately obvious prior
2 to investigation; and

3 “(ii) is either explained upon inves-
4 tigation or remains unexplained.

5 “(3) The terms ‘sudden unexplained death in
6 childhood’ and ‘SUDC’ mean the sudden death of a
7 child 1 year of age or older which remains unex-
8 plained after a thorough case investigation that in-
9 cludes—

10 “(A) a review of the clinical history and
11 circumstances of death; and

12 “(B) performance of a complete autopsy
13 with appropriate ancillary testing.

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

