

SUDDEN UNEXPECTED DEATH DATA ENHANCEMENT AND
 AWARENESS ACT

JULY 24, 2014.—Committed to the Committee of the Whole House on the State of
 the Union and ordered to be printed

Mr. UPTON, from the Committee on Energy and Commerce,
 submitted the following

R E P O R T

[To accompany H.R. 669]

[Including cost estimate of the Congressional Budget Office]

The Committee on Energy and Commerce, to whom was referred the bill (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, having considered the same, report favorably thereon with an amendment and recommend that the bill as amended do pass.

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The amendment is as follows:

Strike all after the enacting clause and insert the following:

SECTION 1. SHORT TITLE.

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

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

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

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

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

“(1) SURVEILLANCE.—

“(A) **IN GENERAL.**—The Secretary shall provide for surveillance efforts to collect thorough, complete, and high-quality epidemiologic information on stillbirths, including through the utilization of existing surveillance systems (including the National Vital Statistics System (NVSS) and other appropriately equipped birth defects surveillance programs).

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

“(i) provide for the continued development and dissemination of a standard protocol for stillbirth data collection and surveillance; and

“(ii) not less than every 5 years, review and, as appropriate, update such protocol.

“(2) **POSTMORTEM DATA COLLECTION AND EVALUATION.**—The Secretary, in consultation with qualified individuals and organizations determined appropriate by the Secretary, to include representatives of health professional organizations, shall—

“(A) upon the enactment of this section, and not less than every 5 years thereafter, review existing guidelines for increasing and improving the quality and completeness of postmortem stillbirth evaluation and related data collection, including conducting and reimbursing autopsies, placental histopathology, and cytogenetic testing; and

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

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

“(1) SURVEILLANCE.—

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

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

“(i) provide for the continued development and dissemination of a standard protocol for SUID data reporting and surveillance; and

“(ii) not less than every 5 years, review and, as appropriate, update such protocol.

“(C) **GOALS FOR ENHANCING SURVEILLANCE.**—In carrying out activities under this subsection, the Secretary shall seek to accomplish the following goals:

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

“(ii) Collecting standardized information about the environmental and medical circumstances of death (including the sleep environment and quality of the death scene investigation).

“(iii) Supporting multidisciplinary infant death reviews, such as those performed by child death review committees, to collect and review the information and classify and characterize SUID using a standardized classification system.

- “(iv) Facilitating the sharing of information to improve the public reporting of surveillance and vital statistics describing the epidemiology of SUID.
- “(2) STANDARD PROTOCOL FOR DEATH SCENE INVESTIGATION.—
- “(A) IN GENERAL.—The Secretary, in consultation with forensic pathologists, medical examiners, coroners, medicolegal death scene investigators, law enforcement personnel, emergency medical technicians and paramedics, public health agencies, and other individuals and organizations determined appropriate by the Secretary, shall—
- “(i) provide for the continued dissemination of a standard death scene investigation protocol; and
- “(ii) not less than every 5 years, review and, as appropriate, update such protocol.
- “(B) CONTENT OF DEATH SCENE PROTOCOL.—The protocol disseminated under subparagraph (A) shall include information on—
- “(i) the current and past medical history of the infant;
- “(ii) family medical history;
- “(iii) the circumstances surrounding the death, including any suspicious circumstances;
- “(iv) the sleep position and sleep environment of the infant; and
- “(v) any accidental or environmental factors associated with death.
- “(3) GUIDELINES FOR A STANDARD AUTOPSY PROTOCOL.—The Secretary, in consultation with the Attorney General of the United States, forensic pathologists, medical examiners, coroners, pediatric pathologists, pediatric cardiologists, pediatric neuropathologists, geneticists, infectious disease specialists, and other individuals and organizations determined appropriate by the Secretary, shall—
- “(A) develop guidelines for a standard autopsy protocol for SUID; and
- “(C) not less than every 5 years, review and, as appropriate, update such guidelines.
- “(4) TRAINING.—The Secretary, in consultation with the Attorney General of the United States, may—
- “(A) conduct or support—
- “(i) training activities for medical examiners, coroners, medicolegal death scene investigators, law enforcement personnel, and emergency medical technicians or paramedics concerning death scene investigations for SUID, including the use of standard death scene investigation protocols disseminated under paragraph (2); and
- “(ii) training activities for medical examiners, coroners, and forensic pathologists concerning standard autopsy protocols for SUID developed under paragraph (3); and
- “(B) make recommendations to health professional organizations regarding the integration of protocols disseminated or developed under this subsection, and training conducted or supported under this paragraph, into existing training and continuing education programs.
- “(c) SUDDEN UNEXPLAINED DEATH IN CHILDHOOD ACTIVITIES.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall continue to carry out activities of the Centers relating to sudden unexpected death in childhood (SUDC), including the following:
- “(1) SURVEILLANCE.—The Secretary, in consultation with the Director of the National Institutes of Health, shall provide for surveillance efforts to gather sociodemographic, death scene investigation, clinical history, and autopsy information on SUDC cases through the review of existing records on SUDC, including through the utilization of existing surveillance systems (including the Sudden Death in the Young Registry).
- “(2) GUIDELINES FOR A STANDARD AUTOPSY PROTOCOL.—The Secretary, in consultation with the Attorney General of the United States, forensic pathologists, medical examiners, coroners, pediatric pathologists, pediatric cardiologists, pediatric neuropathologists, geneticists, infectious disease specialists, and other individuals and organizations determined appropriate by the Secretary, may—
- “(A) develop guidelines for a standard autopsy protocol for SUDC; and
- “(B) not less than every 5 years, review and, as appropriate, update such guidelines.
- “(3) REVIEW OF APPLICABILITY OF PROGRAMS AND ACTIVITIES.—Not later than 18 months after the date of enactment of this section, the Secretary, acting through the Director of the Centers for Disease Control and Prevention, and in consultation with the Director of the National Institutes of Health, shall complete an evaluation of the possibility of carrying out or intensifying, with respect to SUDC, the types of programs and activities that are authorized to be carried out under subsection (b) with respect to SUID.

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

“(1) the results of the evaluation under subsection (c)(3); and

“(2) a description of any activities that—

“(A) are being carried out by the Centers for Disease Control and Prevention in consultation with the National Institutes of Health relating to stillbirth, SUID, or SUDC; and

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

“(e) DEFINITIONS.—In this section:

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

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

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

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

“(A) which occurs suddenly and unexpectedly; and

“(B) whose cause—

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

“(ii) is either explained upon investigation or remains unexplained.

“(3) The terms ‘sudden unexplained death in childhood’ and ‘SUDC’ mean the sudden death of a child 1 year of age or older which remains unexplained after a thorough case investigation that includes—

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

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

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

PURPOSE AND SUMMARY

H.R. 669, the “Sudden Unexpected Death Data Enhancement and Awareness Act,” was introduced on February 13, 2013, by Rep. Pallone (D–NJ) and King (R–NY) to improve the health of children and better understand unexpected sudden death in early life.

BACKGROUND AND NEED FOR LEGISLATION

Fetal death or stillbirth occurs after 20 weeks of pregnancy in about 1 in 160 pregnancies. Causes of stillbirth vary from birth defects to umbilical accidents. Risk factors include maternal age, maternal obesity, and ancestry.¹

Sudden unexpected infant death (SUID) occurs in infants less than 1 year of age. There are about 4,000 infants that die of SUID each year, often with no known cause. Sudden Infant Death Syndrome (SIDS) accounts for half of the SUID cases. The overall rate of SIDS has declined more than 50 percent since 1990, but rates for certain minority groups remain disproportionately higher than the rest of the population.²

Sudden Unexplained Death in Children (SUDC) occurs in children over the age of 12 months, and it often remains unexplained, even after a thorough investigation. SUDC is rare, with an incidence of 1.2 deaths per 100,000 children. Since its cause is unknown, more study is needed to identify prevention strategies.³

Prevention of stillbirth, SUID, and SUDC depends on the collection of data related to the biological, social, and environmental factors associated with these outcomes. The Centers for Disease Con-

¹ <http://www.marchofdimes.com/loss/stillbirth.aspx>.

² <http://www.cdc.gov/sids/aboutsuidandsids.htm>.

³ <http://www.sudc.org/Advocacy/MediaEducation/FactSheet.aspx>.

trol and Prevention (CDC) collects data on stillbirth (fetal death), SUID, and SUDC through its existing surveillance systems in order to identify the extent of the problem and risk factors. Since State reporting procedures vary, the ability of the CDC to collect national data related to stillbirth, SUID, and SUDC has been hampered.⁴

H.R. 669 would authorize activities at the CDC to help improve the understanding of stillbirth, SUID, and SUDC by improving data collection, increasing surveillance strategies, and setting guidelines and protocols for death scene investigations and autopsies.

HEARINGS

On Wednesday, November 20, 2013, the Subcommittee on Health held a hearing on H.R. 669. The Subcommittee received testimony from:

- Marsha Ford, President, American Association of Poison Control Centers;
- Edward McCabe, Office of Medicine and Health Promotion, March of Dimes Foundation;
- Laura Crandall, Co-Founder, Sudden Unexplained Death Program at the CJ Foundation for SIDS;
- Robert Mt. Joy, CEO, Cornerstone Care Inc.;
- Drew Nagele, Board of Directors, Brain Injury Association of America;
- Pat Smith, President, Lyme Disease Association, Inc.; and,
- Steven J. Stack, Board of Trustees, American Medical Association.

COMMITTEE CONSIDERATION

On June 19, 2014, the Subcommittee on Health met in open markup session and forwarded H.R. 669 to the full Committee, as amended, by a voice vote. On July 15, 2014, the Committee on Energy and Commerce met in open markup session and ordered H.R. 669 to be reported to the House, as amended, by a voice vote.

COMMITTEE VOTES

Clause 3(b) of rule XIII of the Rules of the House of Representatives requires the Committee to list the record votes on the motion to report legislation and amendments thereto. There were no record votes taken in connection with ordering H.R. 669 reported. A motion by Mr. Upton to order H.R. 669 reported to the House, as amended, was agreed to by a voice vote

COMMITTEE OVERSIGHT FINDINGS

Pursuant to clause 3(c)(1) of rule XIII of the Rules of the House of Representatives, the Committee held a hearing and made findings that are reflected in this report.

STATEMENT OF GENERAL PERFORMANCE GOALS AND OBJECTIVES

Pursuant to clause 3(c)(1) of rule XIII of the House of Representatives, the goal of H.R. 669 is to help improve the understanding

⁴ <http://www.cdc.gov/sids/suidabout.htm>.

of stillbirth, SUID, and SUDC by improving data collection, increasing surveillance strategies, and setting guidelines and protocols for death scene investigations and autopsies.

NEW BUDGET AUTHORITY, ENTITLEMENT AUTHORITY, AND TAX EXPENDITURES

In compliance with clause 3(c)(2) of rule XIII of the Rules of the House of Representatives, the Committee finds that H.R. 669, would result in no new or increased budget authority, entitlement authority, or tax expenditures or revenues.

EARMARK, LIMITED TAX BENEFITS, AND LIMITED TARIFF BENEFITS

In compliance with clause 9(e), 9(f), and 9(g) of rule XXI of the Rules of the House of Representatives, the Committee finds that H.R. 669 contains no earmarks, limited tax benefits, or limited tariff benefits.

COMMITTEE COST ESTIMATE

The Committee adopts as its own the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974.

CONGRESSIONAL BUDGET OFFICE ESTIMATE

Pursuant to clause 3(c)(3) of rule XIII of the Rules of the House of Representatives, the following is the cost estimate provided by the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974:

U.S. CONGRESS,
CONGRESSIONAL BUDGET OFFICE,
Washington, DC, July 23, 2014.

Hon. FRED UPTON,
*Chairman, Committee on Energy and Commerce,
House of Representatives, Washington, DC.*

DEAR MR. CHAIRMAN: The Congressional Budget Office has prepared the enclosed cost estimate for H.R. 669, the Sudden Unexpected Death Data Enhancement and Awareness Act.

If you wish further details on this estimate, we will be pleased to provide them. The CBO staff contact is Santiago Vallinas.

Sincerely,

DOUGLAS W. ELMENDORF.

Enclosure.

H.R. 669—Sudden Unexpected Death Data Enhancement and Awareness Act

H.R. 669 would require the Secretary of Health and Human Services (HHS), acting through the Centers for Disease Control and Prevention (CDC), to continue to carry out certain activities relating to sudden unexpected death in the young.

The legislation would direct the Secretary of HHS to:

- Support surveillance efforts relating to stillbirths and sudden unexpected death in children, including the development of standard protocols for data collection;

- Promote standard protocols for the investigation of death scenes; and
- Review and update guidelines for post-mortem data collection and for certain types of autopsy examinations.

The CDC currently supports such activities; thus, CBO estimates that requiring those same activities under H.R. 669 would have no incremental cost to the federal government.

The bill would also require the Secretary to submit a report to the Congress on activities relating to stillbirth and sudden deaths in the young. CBO expects that the costs of producing that report would be negligible.

CBO estimates that implementing H.R. 669 would not have a significant effect on federal spending. The bill would not affect direct spending or revenues; therefore, pay-as-you-go procedures do not apply.

H.R. 669 contains no intergovernmental or private-sector mandates as defined in the Unfunded Mandates Reform Act and would impose no costs on state, local, or tribal governments.

The CBO staff contacts for this estimate are Santiago Vallinas and Stephanie Cameron. This estimate was approved by Holly Harvey, Deputy Assistant Director for Budget Analysis.

FEDERAL MANDATES STATEMENT

The Committee adopts as its own the estimate of Federal mandates prepared by the Director of the Congressional Budget Office pursuant to section 423 of the Unfunded Mandates Reform Act.

DUPLICATION OF FEDERAL PROGRAMS

No provision of H.R. 669 establishes or reauthorizes a program of the Federal Government known to be duplicative of another Federal program, a program that was included in any report from the Government Accountability Office to Congress pursuant to section 21 of Public Law 111–139, or a program related to a program identified in the most recent Catalog of Federal Domestic Assistance.

DISCLOSURE OF DIRECTED RULE MAKINGS

The Committee estimates that enacting H.R. 669 would not specifically direct a rulemaking within the meaning of 5 U.S.C. 551.

ADVISORY COMMITTEE STATEMENT

No advisory committees within the meaning of section 5(b) of the Federal Advisory Committee Act were created by this legislation.

APPLICABILITY TO LEGISLATIVE BRANCH

The Committee finds that the legislation does not relate to the terms and conditions of employment or access to public services or accommodations within the meaning of section 102(b)(3) of the Congressional Accountability Act.

SECTION-BY-SECTION ANALYSIS OF THE LEGISLATION

Section 1. Short title

Section 1 states the legislation may be cited as the “Sudden Unexpected Death Data Enhancement and Awareness Act”.

Section 2. Stillbirth and sudden deaths in the young

Section 2 would authorize the continuation of data collection activities related to stillbirth, including the development and dissemination of a standard protocol for surveillance and a review of existing guidelines for postmortem stillbirth evaluation.

The section would allow the continuation of activities related to SUID, including surveillance of various events and records, such as a death scene investigation. A standard protocol for surveillance and death scene investigations related to SUID also would be developed. Guidelines for a standard autopsy protocol would be developed in consultation with Attorney General.

In addition, the section would allow the continuation of activities related to SUDC including surveillance.

Finally, the section would provide for a review of SUID programs and a report to Congress on the implementation of the activities in this section.

CHANGES IN EXISTING LAW MADE BY THE BILL, AS REPORTED

In compliance with clause 3(e) of rule XIII of the Rules of the House of Representatives, changes in existing law made by the bill, as reported, are shown as follows (new matter is printed in italic and existing law in which no change is proposed is shown in roman):

SECTION 317L-1 OF THE PUBLIC HEALTH SERVICE ACT

* * * * *

SEC. 317L-1. STILLBIRTH AND SUDDEN DEATHS IN THE YOUNG.

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

(1) *SURVEILLANCE.*—

(A) *IN GENERAL.*—*The Secretary shall provide for surveillance efforts to collect thorough, complete, and high-quality epidemiologic information on stillbirths, including through the utilization of existing surveillance systems (including the National Vital Statistics System (NVSS) and other appropriately equipped birth defects surveillance programs).*

(B) *STANDARD PROTOCOL FOR SURVEILLANCE.*—*The Secretary, in consultation with qualified individuals and organizations determined appropriate by the Secretary, to include representatives of health and advocacy organizations, State and local governments, public health officials, and health researchers, shall—*

(i) provide for the continued development and dissemination of a standard protocol for stillbirth data collection and surveillance; and

(ii) not less than every 5 years, review and, as appropriate, update such protocol.

(2) *POSTMORTEM DATA COLLECTION AND EVALUATION.*—The Secretary, in consultation with qualified individuals and organizations determined appropriate by the Secretary, to include representatives of health professional organizations, shall—

(A) upon the enactment of this section, and not less than every 5 years thereafter, review existing guidelines for increasing and improving the quality and completeness of postmortem stillbirth evaluation and related data collection, including conducting and reimbursing autopsies, placental histopathology, and cytogenetic testing; and

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

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

(1) *SURVEILLANCE.*—

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

(B) *STANDARD PROTOCOL FOR SURVEILLANCE.*—The Secretary, in consultation with qualified individuals and organizations determined appropriate by the Secretary, to include representatives of health and advocacy organizations, State and local governments, and public health officials, shall—

(i) provide for the continued development and dissemination of a standard protocol for SUID data reporting and surveillance; and

(ii) not less than every 5 years, review and, as appropriate, update such protocol.

(C) *GOALS FOR ENHANCING SURVEILLANCE.*—In carrying out activities under this subsection, the Secretary shall seek to accomplish the following goals:

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

(ii) Collecting standardized information about the environmental and medical circumstances of death (including the sleep environment and quality of the death scene investigation).

(iii) Supporting multidisciplinary infant death reviews, such as those performed by child death review committees, to collect and review the information and classify and characterize SUID using a standardized classification system.

- (iv) *Facilitating the sharing of information to improve the public reporting of surveillance and vital statistics describing the epidemiology of SUID.*
- (2) *STANDARD PROTOCOL FOR DEATH SCENE INVESTIGATION.—*
- (A) *IN GENERAL.—The Secretary, in consultation with forensic pathologists, medical examiners, coroners, medicolegal death scene investigators, law enforcement personnel, emergency medical technicians and paramedics, public health agencies, and other individuals and organizations determined appropriate by the Secretary, shall—*
- (i) *provide for the continued dissemination of a standard death scene investigation protocol; and*
- (ii) *not less than every 5 years, review and, as appropriate, update such protocol.*
- (B) *CONTENT OF DEATH SCENE PROTOCOL.—The protocol disseminated under subparagraph (A) shall include information on—*
- (i) *the current and past medical history of the infant;*
- (ii) *family medical history;*
- (iii) *the circumstances surrounding the death, including any suspicious circumstances;*
- (iv) *the sleep position and sleep environment of the infant; and*
- (v) *any accidental or environmental factors associated with death.*
- (3) *GUIDELINES FOR A STANDARD AUTOPSY PROTOCOL.—The Secretary, in consultation with the Attorney General of the United States, forensic pathologists, medical examiners, coroners, pediatric pathologists, pediatric cardiologists, pediatric neuropathologists, geneticists, infectious disease specialists, and other individuals and organizations determined appropriate by the Secretary, shall—*
- (A) *develop guidelines for a standard autopsy protocol for SUID; and*
- (C) *not less than every 5 years, review and, as appropriate, update such guidelines.*
- (4) *TRAINING.—The Secretary, in consultation with the Attorney General of the United States, may—*
- (A) *conduct or support—*
- (i) *training activities for medical examiners, coroners, medicolegal death scene investigators, law enforcement personnel, and emergency medical technicians or paramedics concerning death scene investigations for SUID, including the use of standard death scene investigation protocols disseminated under paragraph (2); and*
- (ii) *training activities for medical examiners, coroners, and forensic pathologists concerning standard autopsy protocols for SUID developed under paragraph (3); and*
- (B) *make recommendations to health professional organizations regarding the integration of protocols disseminated or developed under this subsection, and training conducted or supported under this paragraph, into existing training and continuing education programs.*

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

(1) *SURVEILLANCE.*—The Secretary, in consultation with the Director of the National Institutes of Health, shall provide for surveillance efforts to gather sociodemographic, death scene investigation, clinical history, and autopsy information on SUDC cases through the review of existing records on SUDC, including through the utilization of existing surveillance systems (including the Sudden Death in the Young Registry).

(2) *GUIDELINES FOR A STANDARD AUTOPSY PROTOCOL.*—The Secretary, in consultation with the Attorney General of the United States, forensic pathologists, medical examiners, coroners, pediatric pathologists, pediatric cardiologists, pediatric neuropathologists, geneticists, infectious disease specialists, and other individuals and organizations determined appropriate by the Secretary, may—

(A) develop guidelines for a standard autopsy protocol for SUDC; and

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

(3) *REVIEW OF APPLICABILITY OF PROGRAMS AND ACTIVITIES.*—Not later than 18 months after the date of enactment of this section, the Secretary, acting through the Director of the Centers for Disease Control and Prevention, and in consultation with the Director of the National Institutes of Health, shall complete an evaluation of the possibility of carrying out or intensifying, with respect to SUDC, the types of programs and activities that are authorized to be carried out under subsection (b) with respect to SUID.

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

(1) the results of the evaluation under subsection (c)(3); and

(2) a description of any activities that—

(A) are being carried out by the Centers for Disease Control and Prevention in consultation with the National Institutes of Health relating to stillbirth, SUID, or SUDC; and

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

(e) *DEFINITIONS.*—In this section:

(1) The term “stillbirth” means a spontaneous fetal death that—

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

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

(2) The terms “sudden unexpected infant death” and “SUID” mean the death of an infant less than 1 year of age—

(A) which occurs suddenly and unexpectedly; and

(B) whose cause—

- (i) is not immediately obvious prior to investigation;*
- and*
- (ii) is either explained upon investigation or remains unexplained.*

(3) The terms “sudden unexplained death in childhood” and “SUDC” mean the sudden death of a child 1 year of age or older which remains unexplained after a thorough case investigation that includes—

- (A) a review of the clinical history and circumstances of death; and*
- (B) performance of a complete autopsy with appropriate ancillary testing.*

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

