

110TH CONGRESS  
2D SESSION

# S. 3142

To amend the Public Health Service Act to enhance public health activities related to stillbirth and sudden unexpected infant death.

---

IN THE SENATE OF THE UNITED STATES

JUNE 17, 2008

Mr. REID (for Mr. OBAMA) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

---

## A BILL

To amend the Public Health Service Act to enhance public health activities related to stillbirth and sudden unexpected infant death.

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 “Preventing Stillbirth  
5       and SUID Act of 2008”.

6       **SEC. 2. FINDINGS.**

7       Congress makes the following findings:

8               (1) Every year, more than 25,000 women in the  
9       United States experience stillbirth.

1           (2) Common diagnosable causes for stillbirth  
2 include genetic abnormalities, umbilical cord acci-  
3 dents, infections, and placental problems, however,  
4 more than half of all stillbirths remain unexplained.

5           (3) A number of risk factors for stillbirth have  
6 been described in pregnant women such as maternal  
7 age, obesity, smoking, diabetes, hypertension, and  
8 previous stillbirth.

9           (4) Good prenatal care, not smoking, and not  
10 drinking alcohol are helpful strategies for pregnant  
11 women to reduce the risk of stillbirth, however, re-  
12 searchers continue to perform studies into other ef-  
13 fective modes of reducing the risk, including moni-  
14 toring fetal activity or “in utero” movement starting  
15 at approximately 28 weeks.

16           (5) Half of the more than 4,500 sudden, unex-  
17 pected infant deaths (SUID) that occur each year in  
18 the United States are due to sudden infant death  
19 syndrome (SIDS), which is the leading cause of  
20 SUID and of all deaths among infants aged 1 to 12  
21 months.

22           (6) Sudden infant death syndrome is a diag-  
23 nosis of exclusion and is only determined after all  
24 known causes are excluded by a thorough examina-  
25 tion of the death scene, a review of the clinical his-

tory, and performance of an autopsy. However, some SUID are not investigated and, even when they are, cause-of-death data are not collected and reported consistently.

(7) Inaccurate classification of cause and manner of death impedes prevention efforts and complicates our ability to understand risk factors related to these deaths.

(8) Death certificate data cannot fully characterize the sudden, unexpected infant deaths nor identify potential risk factors amenable to prevention.

**SEC. 3. ENHANCING PUBLIC HEALTH ACTIVITIES RELATED TO STILLBIRTH.**

(a) IN GENERAL.—Part B of title XI of the Public Health Service Act (42 U.S.C. 300c–12 et seq.) is amended by adding at the end the following:

**“SEC. 1123. NATIONAL REGISTRY AND PUBLIC HEALTH PROGRAMS FOR STILLBIRTH.**

**“(a) DETERMINATION OF STANDARD STILLBIRTH DEFINITION AND PROTOCOL.—**

**“(1) IN GENERAL.—**For purposes of this section, the Secretary shall provide for the development of—

**“(A) a standard definition of stillbirth; and**

1 “(B) a standard protocol for stillbirth data  
2 collection and surveillance, including—

3 “(i) enhancing the National Vital Sta-  
4 tistics System for the reporting of still-  
5 births; and

6 “(ii) expanding active population-  
7 based surveillance efforts currently under-  
8 way at the Centers for Disease Control and  
9 Prevention, including utilizing the infra-  
10 structure of existing birth defects surveil-  
11 lance registries to collect thorough and  
12 complete epidemiologic information on still-  
13 births.

14 “(2) CONSULTATION.—The Secretary shall en-  
15 sure that the standard definition and protocol de-  
16 scribed in paragraph (1) are developed in a manner  
17 that ensures the consultation of representatives of  
18 health and advocacy organizations, State and local  
19 governments, and other interested entities specified  
20 by the Secretary.

21 “(b) ESTABLISHMENT.—The Secretary, acting  
22 through the Administrator of the Health Resources and  
23 Services Administration, the Director of the Centers for  
24 Disease Control and Prevention, and the Director of the  
25 National Institutes of Health, and in consultation with na-

1 tional health organizations and professional societies with  
 2 expertise relating to reducing stillbirths and infant mor-  
 3 tality, shall establish—

4 “(1) a national registry that can facilitate the  
 5 understanding of root causes, rates, and trends of  
 6 stillbirth; and

7 “(2) public education and prevention programs  
 8 aimed at reducing the occurrence of stillbirth.

9 “(c) NATIONAL REGISTRY.—The national registry es-  
 10 tablished under subsection (b)(1) shall facilitate the collec-  
 11 tion, analysis, and dissemination of data by—

12 “(1) implementing a surveillance and moni-  
 13 toring system based on the protocols developed in  
 14 subsection (a)(1)(B);

15 “(2) developing standardized protocols for thor-  
 16 ough and complete investigation of stillbirth, includ-  
 17 ing protocols for autopsy and pathological examina-  
 18 tions of the fetus and placenta, and other post-  
 19 mortem tests for surveillance of stillbirth;

20 “(3) identifying trends, potential risk factors  
 21 for further study, and methods for the evaluation of  
 22 prevention efforts; and

23 “(4) supporting efforts in collection of vital  
 24 records, active case finding, linkage studies, and

1 other epidemiologic efforts to identify potential risk  
 2 factors and prevention opportunities.

3 “(d) PUBLIC EDUCATION AND PREVENTION PRO-  
 4 GRAMS.—The Secretary, acting through the Director of  
 5 the Centers for Disease Control and Prevention and the  
 6 Director of the National Institutes of Health, shall directly  
 7 or through grants, cooperative agreements, or contracts  
 8 to eligible entities, develop and conduct public education  
 9 and prevention programs established under subsection  
 10 (b)(2), including—

11 “(1) public education programs, services, and  
 12 demonstrations which are designed to increase gen-  
 13 eral awareness of stillbirths; and

14 “(2) the development of tools for the education  
 15 of health professionals and pregnant women about  
 16 the early-warning signs of stillbirth, which may in-  
 17 clude monitoring of fetal movement or baby in-utero.

18 “(e) AUTHORIZATION OF APPROPRIATIONS.—There  
 19 are authorized to be appropriated to carry out this section,  
 20 \$5,000,000 for fiscal year 2009 and such sums as may  
 21 be necessary for each of fiscal years 2010 through 2013.”.

22 (b) CONFORMING AMENDMENT.—The heading of  
 23 part B of title XI of the Public Health Service Act (42  
 24 U.S.C. 300c–12 et seq.) is amended by adding at the end  
 25 the following: “**AND STILLBIRTH**”.

1 **SEC. 4. ENHANCING PUBLIC HEALTH ACTIVITIES RELATED**  
 2 **TO SUDDEN UNEXPECTED INFANT DEATH.**

3 (a) IN GENERAL.—Part B of title XI of the Public  
 4 Health Service Act (42 U.S.C. 300c–12 et seq.), as  
 5 amended by section 3, is further amended by adding at  
 6 the end the following:

7 **“SEC. 1124. NATIONAL REGISTRY FOR SUDDEN UNEX-**  
 8 **PECTED INFANT DEATHS.**

9 “(a) DEFINITION.—In this section, the term ‘sudden,  
 10 unexpected infant deaths’ (referred to in this section as  
 11 ‘SUID’) means infant deaths that have no obvious cause  
 12 of death, are not the result of a chronic disease or known  
 13 illness, are unexpected, and not explainable without a  
 14 more careful examination. These deaths may include  
 15 deaths due to suffocation, poisoning, injuries, falls, sudden  
 16 infant death syndrome, or previously unrecognized illness  
 17 or disorder.

18 “(b) ESTABLISHMENT.—The Secretary, acting  
 19 through the Administrator of the Health Resources and  
 20 Services Administration, the Director of the Centers for  
 21 Disease Control and Prevention, and the Director of the  
 22 National Institutes of Health, and in consultation with na-  
 23 tional health organizations and professional societies with  
 24 experience and expertise relating to reducing SUID, shall  
 25 establish a population-based SUID case registry that can

1 facilitate the understanding of the root causes, rates, and  
2 trends of SUID.

3 “(c) NATIONAL REGISTRY.—The national registry es-  
4 tablished under subsection (b) shall facilitate the collec-  
5 tion, analysis, and dissemination of data by—

6 “(1) implementing a surveillance and moni-  
7 toring system based on thorough and complete death  
8 scene investigation data, clinical history, and au-  
9 topsy findings;

10 “(2) collecting standardized information about  
11 the environmental, medical, social, and genetic cir-  
12 cumstances that may correlate with infant deaths  
13 (including sleep environment and the quality of the  
14 death scene investigation) from the SUID Initiative  
15 Reporting Form or equivalent, as well as other law  
16 enforcement, medical examiner, coroner, emergency  
17 medical services (EMS), and medical records;

18 “(3) promoting the use of Centers for Disease  
19 Control and Prevention standardized SUID death  
20 investigation and reporting tools as well as standard-  
21 ized autopsy protocols;

22 “(4) establishing a standardized classification  
23 system for defining subcategories of SIDS and  
24 SUID for surveillance and prevention research ac-  
25 tivities;



1           “(5) supporting multidisciplinary infant death  
 2       reviews such as those performed by child death re-  
 3       view committees and fetal infant mortality commit-  
 4       tees to collect and review the standardized informa-  
 5       tion and accurately and consistently classify and  
 6       characterize SUID; and

7           “(6) improving public reporting of surveillance  
 8       and descriptive epidemiology of SUID by  
 9       supplementing vital statistics data.

10       “(d) AUTHORIZATION OF APPROPRIATIONS.—There  
 11   are authorized to be appropriated to carry out this section,  
 12   \$5,000,000 for fiscal year 2009 and such sums as nec-  
 13   essary for each of fiscal years 2010 through 2013.”.

14       (b) CONFORMING AMENDMENT.—The heading of  
 15   part B of title XI of the Public Health Service Act (42  
 16   U.S.C. 300c–12 et seq.), as amended by section 3, is fur-  
 17   ther amended by adding at the end the following: “, **AND**  
 18   **SUDDEN UNEXPECTED INFANT DEATH**”.

○