

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-

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

5 (7) Inaccurate classification of cause and man-
 6 ner of death impedes prevention efforts and com-
 7 plicates our ability to understand risk factors related
 8 to these deaths.

9 (8) Death certificate data cannot fully charac-
 10 terize the sudden, unexpected infant deaths nor
 11 identify potential risk factors amenable to preven-
 12 tion.

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

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

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

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

22 “(1) IN GENERAL.—For purposes of this sec-
 23 tion, the Secretary shall provide for the development
 24 of—

25 “(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. 300e–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**”.

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