S. 1862

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

IN THE SENATE OF THE UNITED STATES

NOVEMBER 15, 2011

Mr. Lautenberg (for himself, Ms. Snowe, Mr. Kerry, Mr. Johnson of South Dakota, Mrs. Hagan, and Mr. Menendez) 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 improve the health of children and reduce the occurrence of sudden unexpected infant death and to enhance public health activities related to stillbirth.

- 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 "Stillbirth and SUID
- 5 Prevention, Education, and Awareness Act of 2011".
- 6 SEC. 2. FINDINGS.
- 7 Congress makes the following findings:

- 1 (1) Every year, there are more than 25,000 2 stillbirths in the United States.
 - (2) Causes for stillbirth include genetic abnormalities, umbilical cord accidents, infections, and placental problems.
 - (3) A number of risk factors for stillbirth have been described in pregnant women such as young or advanced maternal age, obesity, smoking, diabetes, and hypertension.
 - (4) Because of advances in medical care over the last 30 years, much more is known about the causes of stillbirth. But for as many as 50 percent of stillbirths, the cause is never identified.
 - (5) Sudden unexpected infant death (SUID) is the sudden death of an infant under 1 year of age that when first discovered did not have an obvious cause. These include those deaths that are later determined to be from explained as well as unexplained causes.
 - (6) In 2004, approximately 4,600 infants died suddenly and unexpectedly of no immediate obvious cause.
 - (7) Each year approximately 200 deaths of children between the ages of 1 and 4 remain unex-

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- plained after a thorough case investigation is conducted.
 - (8) The Sudden Unexpected Infant Death (SUID) rate has been declining significantly since the early 1990s. However, research has found that some of the decline in SUID since 1999 can be explained by diagnostic shifts and increasing diagnosis specificity.
 - (9) Many sudden unexpected infant deaths are not investigated and, even when they are, cause-of-death data are not collected and reported consistently.
 - (10) Inaccurate or inconsistent classification of cause and manner of death due to inconsistent data collection impedes prevention efforts and complicates the ability to understand risk factors related to these deaths.
 - (11) The National Child Death Review Case Reporting System collects comprehensive information on the risk factors associated with SUID deaths. As of March 2011, 37 of the 49 States conducting child death reviews are voluntarily submitting data to this reporting system.

1	SEC. 3. AMENDMENT TO THE PUBLIC HEALTH SERVICE
2	ACT.
3	Title III of the Public Health Service Act (42 U.S.C.
4	241 et seq.) is amended by adding at the end the fol-
5	lowing:
6	"PART W—SUDDEN UNEXPECTED INFANT DEATH
7	AND SUDDEN UNEXPLAINED DEATH IN
8	CHILDHOOD
9	"SEC. 39900. DEFINITIONS.
10	"In this part:
11	"(1) Administrator.—The term 'Adminis-
12	trator' means the Administrator of the Health Re-
13	sources and Services Administration.
14	"(2) DIRECTOR.—The term 'Director' means
15	the Director of the Centers for Disease Control and
16	Prevention.
17	"(3) State.—The term 'State' has the mean-
18	ing given to such term in section 2, except that such
19	term includes tribes and tribal organizations (as
20	such terms are defined in section 4 of the Indian
21	Self-Determination and Education Assistance Act).
22	"(4) Sudden unexpected infant death;
23	SUID.—The terms 'sudden unexpected infant death'
24	and 'SUID' mean the sudden death of an infant
25	under 1 year of age that when first discovered did

not have an obvious cause. Such terms include those

deaths that are later determined to be from explained as well as unexplained causes.

3 "(5) SUDDEN UNEXPLAINED DEATH IN CHILD-4 HOOD; SUDC.—The terms 'sudden unexplained death 5 in childhood' and 'SUDC' mean the sudden death of 6 a child older than 1 year of age which remains unex-7 plained after a thorough case investigation that in-8 cludes a review of the clinical history and cir-9 cumstances of death and performance of a complete 10 autopsy with appropriate ancillary testing.

11 "SEC. 39900-1. DEATH SCENE INVESTIGATION AND AU-

- 12 **TOPSY.**
- 13 "(a) Investigations.—
- "(1) Grants.—The Secretary, acting through the Director, shall award grants to States to enable such States to improve the completion of comprehensive death scene investigations for sudden unexpected infant death and sudden unexplained death in childhood.
 - "(2) APPLICATION.—To be eligible to receive a grant under paragraph (1), a State shall submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require.
- 25 "(3) Use of funds.—

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"(A) IN GENERAL.—A State shall use amounts received under a grant under paragraph (1) to improve the completion of comprehensive death scene investigations for sudden unexpected infant death and sudden unexplained death in childhood, including through the awarding of subgrants to local jurisdictions to be used to implement standard death scene investigation protocols for sudden unexpected infant death and sudden unexplained death in childhood and conduct comprehensive, standardized autopsies.

Protocols.—A "(B) standard death scene protocol implemented under subparagraph (A) shall include the obtaining of information on current and past medical history of the infant/child, the circumstances surrounding the death including any suspicious circumstances, the sleep position and sleep environment of the infant/child, and whether there were any accidental or environmental factors associated with the death. The Director in consultation with medical examiners, coroners, death scene investigators, law enforcement, emergency medical technicians and paramedics, public health agencies, and other individuals or groups determined
necessary by the Director shall develop a standard death scene protocol for children from 1 to
4 years of age, using existing protocols developed for SUID.

"(b) Autopsies.—

- "(1) IN GENERAL.—The Secretary, acting through the Director, shall award grants to States to enable such States to increase the rate at which comprehensive, standardized autopsies are performed for sudden unexpected infant death and sudden unexplained death in childhood.
- "(2) APPLICATION.—To be eligible to receive a grant under paragraph (1), a State shall submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require.
- "(3) Comprehensive autopsy.—For purposes of this subsection, a comprehensive autopsy shall include a full external and internal examination, including microscopic examination, of all major organs and tissues including the brain, complete radiographs, vitreous fluid analysis, photo documentation, selected microbiology when indicated,

1 metabolic testing, and toxicology screening of the in-2 fant or child involved.

> "(4) Guidelines.—The Director, in consultation with board certified forensic pathologists, medical examiners, coroners, pediatric pathologists, pediatric cardiologists, pediatric neuropathologists and geneticists, and other individuals and groups determined necessary by the Director shall develop national guidelines for a standard autopsy protocol for sudden unexpected infant death and sudden unexplained death in childhood. The Director shall ensure that the majority of such consultation is with board certified forensic pathologists, medical examiners, and coroners. The Director is encouraged to seek additional input from child abuse experts, bereavement specialists, parents, and public health agencies on nonmedical aspects of the autopsy guidelines. In developing such protocol, the Director shall consider autopsy protocols used by State and local jurisdictions.

"(c) Study on Genetic Testing.—The Director, in consultation with medical examiners, coroners, forensic pathologists, geneticists, researchers, public health officials, and other individuals and groups determined necessary by the Director, shall commission a study to deter-

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- 1 mine the benefits and appropriateness of genetic testing
- 2 for infant and early childhood deaths that remain unex-
- 3 plained after a complete death scene investigation and
- 4 comprehensive, standardized autopsy. Such study shall in-
- 5 clude recommendations on developing a standard protocol
- 6 for use in determining when to utilize genetic testing and
- 7 standard protocols for the collection and storage of speci-
- 8 mens suitable for genetic testing.
- 9 "(d) AUTHORIZATION OF APPROPRIATIONS.—There
- 10 is authorized to be appropriated \$8,000,000 for each of
- 11 fiscal years 2012 through 2016 to carry out this section.
- 12 "SEC. 39900-2. TRAINING.
- 13 "(a) Grants.—The Secretary, acting through the
- 14 Director, shall award grants to eligible entities for the pro-
- 15 vision of training on death scene investigation specific for
- 16 SUID and SUDC.
- 17 "(b) Eligible Entities.—To be eligible to receive
- 18 a grant under subsection (a), an entity shall—
- 19 "(1) be—
- 20 "(A) a State or local government entity; or
- 21 "(B) a nonprofit private entity; and
- "(2) submit to the Secretary an application at
- such time, in such manner, and containing such in-
- formation as the Secretary may require.

1 "(c) Use of Funds.—An eligible entity shall use 2 amounts received under a grant under this section to— 3 "(1) provide training to medical examiners, 4 coroners, death scene investigators, law enforcement 5 personnel, and emergency medical technicians or 6 paramedics concerning death scene investigations for 7 SUID and SUDC, including the use of standard 8 death scene investigation protocols that include in-9 formation on the current and past medical history of 10 the infant/child, the circumstances surrounding the 11 death including any suspicious circumstances, the 12 sleep position and sleep environment of the infant/ 13 child, and whether there were any accidental or envi-14 ronmental factors associated with the death; 15 "(2) provide training directly to individuals who 16 are responsible for conducting and reviewing death

"(2) provide training directly to individuals who are responsible for conducting and reviewing death scene investigations for sudden unexpected infant death and sudden unexplained death in childhood;

"(3) provide training to multidisciplinary teams, including teams that have a medical examiner or coroner, death scene investigator, law enforcement representative, and an emergency medical technician or paramedic;

"(4) in the case of national and State-based grantees that are comprised of medical examiners,

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- coroners, death scene investigators, law enforcement personnel, or emergency medical technicians and paramedics, integrate training under the grant on death scene investigation of SUID and SUDC into professional accreditation and training programs;
 - "(5) in the case of State and local government entity grantees, obtain equipment, including computer equipment, to aid in the completion of standard death scene investigation; or
 - "(6) conduct training activities for medical examiners, coroners, and forensic pathologists concerning standard autopsy protocols for sudden unexpected infant death and sudden unexplained death in childhood and integrate the training under the grant on standard autopsy protocols in SUID and SUDC into professional accreditation and training programs.
- 18 "(d) AUTHORIZATION OF APPROPRIATIONS.—There 19 is authorized to be appropriated to carry out this section 20 \$2,000,000 for each of fiscal years 2012 through 2016.
- 21 "SEC. 39900-3. CHILD DEATH REVIEW.
- 22 "(a) Prevention.—
- "(1) CORE CAPACITY GRANTS.—The Secretary,
 acting through the Administrator, shall award
 grants to States to build and strengthen State ca-

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- pacity and implement State and local child death re view programs and prevention strategies.
- "(2) Planning Grants.—The Secretary, acting through the Administrator, shall award planning grants to States that have no existing child death review program or States in which the only child death review programs are State-based, for the development of local child death review programs and prevention strategies.
 - "(3) APPLICATION.—To be eligible to receive a grant under paragraph (1) or (2), a State shall submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require.
 - "(4) TECHNICAL ASSISTANCE.—The Secretary, acting through the Administrator, shall provide technical assistance to assist States—
- 18 "(A) in developing the capacity for com-19 prehensive child death review programs, includ-20 ing the development of best practices for the 21 implementation of such programs; and
- 22 "(B) in maintaining the national child 23 death case reporting system.
- 24 "(b) AUTHORIZATION OF APPROPRIATIONS.—There 25 is authorized to be appropriated \$7,000,000 for each of

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1	fiscal years 2012 through 2016 to carry out subsection
2	(a).
3	"SEC. 39900-4. NATIONAL REGISTRY FOR SUDDEN UNEX-
4	PECTED INFANT DEATHS AND SUDDEN UNEX-
5	PLAINED DEATH IN CHILDHOOD.
6	"(a) Establishment.—The Secretary, acting
7	through the Director and in consultation with the national
8	child death case reporting system, national health organi-
9	zations, and professional societies with experience and ex-
10	pertise relating to reducing SUID and SUDC, shall estab-
11	lish a population-based SUID and SUDC case registry
12	that can facilitate the understanding of the root causes,
13	rates, and trends of SUID and SUDC.
14	"(b) National Registry.—The national registry
15	established under subsection (a) shall facilitate the collec-
16	tion, analysis, and dissemination of data by—
17	"(1) implementing a surveillance and moni-
18	toring system based on thorough and complete death
19	scene investigation data, clinical history, and au-
20	topsy findings;
21	"(2) collecting standardized information about
22	the environmental, medical, genetic, and social cir-
23	cumstances of death (including sleep environment
24	and quality of the death scene investigation) if de-
25	termined that such may correlate with infant and

- 1 early childhood deaths, as well as information from
- 2 other law enforcement, medical examiner, coroner,
- 3 emergency medical services (EMS), medical records,
- 4 and vital records (if possible);
- 5 "(3) supporting multidisciplinary infant and
- 6 early childhood death reviews such as those per-
- 7 formed by child death review committees to collect
- 8 and review the standardized information and accu-
- 9 rately and consistently classify and characterize
- 10 SUID and SUDC;
- 11 "(4) facilitating the sharing of information to
- improve the public reporting of surveillance and vital
- statistics describing the epidemiology of SUID and
- 14 SUDC; and
- 15 "(5) utilizing current infrastructure of existing
- surveillance systems.
- 17 "(c) Authorization of Appropriations.—There
- 18 is authorized to be appropriated to carry out this section
- 19 \$3,000,000 for each of fiscal years 2012 through 2016.
- 20 "SEC. 39900-5. PUBLIC AWARENESS AND EDUCATION CAM-
- 21 PAIGN.
- 22 "(a) Establishment.—The Secretary, acting
- 23 through the Administrator and in consultation with the
- 24 Director and the Director of the National Institutes of
- 25 Health, shall establish and implement a culturally com-

- 1 petent research-based public health awareness and edu-
- 2 cation campaign to provide information that is focused on
- 3 decreasing the risk factors that contribute to sudden unex-
- 4 pected infant death and sudden unexplained death in
- 5 childhood, including educating individuals and organiza-
- 6 tions about safe sleep environments, sleep positions, and
- 7 reducing exposure to smoking during pregnancy and after
- 8 birth.
- 9 "(b) Targeted Populations.—The campaign
- 10 under subsection (a) shall be designed to reduce health
- 11 disparities through the targeting of populations with high
- 12 rates of sudden unexpected infant death and sudden unex-
- 13 plained death in childhood.
- 14 "(c) Consultation.—In establishing and imple-
- 15 menting the campaign under subsection (a), the Secretary
- 16 shall consult with national organizations representing
- 17 health care providers, including nurses and physicians,
- 18 parents, child care providers, children's advocacy and safe-
- 19 ty organizations, maternal and child health programs and
- 20 women's, infants', and children's nutrition professionals,
- 21 and other individuals and groups determined necessary by
- 22 the Secretary for such establishment and implementation.
- 23 "(d) Grants.—
- 24 "(1) In General.—In carrying out the cam-
- paign under subsection (a), the Secretary shall

- 1 award grants to national organizations, State and
- 2 local health departments, and community-based or-
- 3 ganizations for the conduct of education and out-
- 4 reach programs for health care providers, parents,
- 5 child care providers, public health agencies, and
- 6 community organizations.
- 7 "(2) APPLICATION.—To be eligible to receive a
- 8 grant under paragraph (1), an entity shall submit to
- 9 the Secretary an application at such time, in such
- manner, and containing such information as the Sec-
- 11 retary may require.
- 12 "(e) Authorization of Appropriations.—There
- 13 is authorized to be appropriated to carry out this section
- 14 \$7,000,000 for fiscal year 2012 and \$5,000,000 for each
- 15 of fiscal years 2013 through 2016.
- 16 "SEC. 39900-6. GRANTS FOR SUPPORT SERVICES.
- 17 "(a) IN GENERAL.—The Secretary, acting through
- 18 the Administrator, shall award grants to national organi-
- 19 zations, State and local health departments, and commu-
- 20 nity-based organizations, for the provisions of support
- 21 services to families who have had a child die of sudden
- 22 unexpected infant death and sudden unexplained death in
- 23 childhood.
- 24 "(b) APPLICATION.—To be eligible to receive a grant
- 25 under subsection (a), an entity shall submit to the Sec-

- 1 retary an application at such time, in such manner, and
- 2 containing such information as the Secretary may require.
- 3 "(c) Use of Funds.—Amounts received under a
- 4 grant awarded under subsection (a) may be used to pro-
- 5 vide grief counseling, education, home visits, 24-hour hot-
- 6 lines, and support groups for families who have lost a child
- 7 to sudden unexpected infant death or sudden unexplained
- 8 death in childhood.
- 9 "(d) Preference.—In awarding grants under sub-
- 10 section (a), the Secretary shall give preference to commu-
- 11 nity-based applicants that have a proven history of effec-
- 12 tive direct support services and interventions for sudden
- 13 unexpected infant death and sudden unexplained death in
- 14 childhood and can demonstrate experience through col-
- 15 laborations and partnerships for delivering services
- 16 throughout a State or region.
- 17 "(e) Authorization of Appropriations.—There
- 18 is authorized to be appropriated to carry out this section
- 19 \$500,000 for each of fiscal years 2012 through 2016.
- 20 "SEC. 39900-7. EVALUATION OF STATE AND REGIONAL
- 21 NEEDS.
- 22 "(a) In General.—The Secretary, acting through
- 23 the Director and in consultation with the Administrator,
- 24 shall conduct a needs assessment on a State and regional
- 25 basis of the availability of personnel, training, technical

- 1 assistance, and resources for investigating and deter-
- 2 mining sudden unexpected infant death and sudden unex-
- 3 plained death in childhood and make recommendations to
- 4 increase collaboration on a State and regional level for in-
- 5 vestigation and determination.
- 6 "(b) AUTHORIZATION OF APPROPRIATIONS.—There
- 7 is authorized to be appropriated to carry out this section,
- 8 \$250,000 for each of fiscal years 2012 through 2016.".
- 9 SEC. 4. ENHANCING PUBLIC HEALTH ACTIVITIES RELATED
- 10 TO STILLBIRTH.
- 11 Part P of title III of the Public Health Service Act
- 12 (42 U.S.C. 280g et seq.) is amended by adding at the end
- 13 the following:
- 14 "SEC. 399V-5, ENHANCING PUBLIC HEALTH ACTIVITIES RE-
- 15 LATED TO STILLBIRTH.
- 16 "(a) Grants.—The Secretary, acting through the
- 17 Director of the Centers for Disease Control and Preven-
- 18 tion, shall award grants to eligible States and metropolitan
- 19 areas to enhance and expand surveillance efforts to collect
- 20 thorough and complete epidemiologic information on still-
- 21 births, including through the utilization of the infrastruc-
- 22 ture of existing surveillance systems (including vital statis-
- 23 tics systems).
- 24 "(b) Eligibility.—To be eligible to receive a grant
- 25 under subsection (a), an entity shall—

1	"(1) be a State or a major metropolitan area
2	(as defined by the Secretary); and
3	"(2) submit to the Secretary an application at
4	such time, in such manner, and containing such in-
5	formation as the Secretary may require, including—
6	"(A) an assurance that the applicant will
7	implement the standardized surveillance pro-
8	tocol developed under subsection (c); and
9	"(B) a description of the infrastructure of
10	existing surveillance systems in the State or
11	major metropolitan area, as applicable.
12	"(c) Surveillance Protocol.—The Secretary,
13	acting through the Director of the Centers for Disease
14	Control and Prevention, shall—
15	"(1) provide for the continued development and
16	dissemination of a standard protocol for stillbirth
17	data collection and surveillance, in consultation with
18	representatives of health and advocacy organizations,
19	State and local governments, and other interested
20	entities determined appropriate by the Secretary;
21	"(2) monitor trends and identify potential risk
22	factors for further study using existing sources of
23	surveillance data and expanded sources of data from
24	targeted surveillance efforts, and methods for the
25	evaluation of stillbirth prevention efforts: and

1	"(3) develop and evaluate methods to link exist-
2	ing data to provide more complete information for
3	research into the causes and conditions associated
4	with stillbirth.
5	"(d) Postmortem Evaluation and Data Collec-
6	TION.—The Secretary, acting through the Director of the
7	Centers for Disease Control and Prevention and in con-
8	sultation with physicians, nurses, pathologists, geneticists,
9	parents, and other groups determined necessary by the Di-
10	rector, shall develop guidelines for increasing the perform-
11	ance and data collection of postmortem stillbirth evalua-
12	tion, including conducting and reimbursing autopsies, pla-
13	cental histopathology, and cytogenetic testing. The guide-
14	lines should take into account cultural competency issues
15	related to postmortem stillbirth evaluation.
16	"(e) Public Health Programmatic Activities
17	RELATED TO STILLBIRTH.—The Secretary, acting
18	through the Director of the Centers for Disease Control
19	and Prevention, shall—
20	"(1) develop behavioral surveys for women ex-
21	periencing stillbirth, using existing State-based in-
22	frastructure for pregnancy-related information gath-
23	ering; and
24	"(2) increase the technical assistance provided
25	to States, Indian tribes, territories, and local com-

- 1 munities to enhance capacity for improved investiga-
- 2 tion of medical and social factors surrounding still-
- 3 birth events.
- 4 "(f) Public Education and Prevention Pro-
- 5 GRAMS.—The Secretary, acting through the Director of
- 6 the Centers for Disease Control and Prevention and in
- 7 consultation with health care providers, public health or-
- 8 ganizations, maternal and child health programs, parents,
- 9 and other groups deemed necessary by the Director, shall
- 10 directly or through grants, cooperative agreements, or con-
- 11 tracts to eligible entities, develop and conduct evidence-
- 12 based public education and prevention programs aimed at
- 13 reducing the occurrence of stillbirth overall and addressing
- 14 the racial and ethnic disparities in its occurrence, includ-
- 15 ing—
- 16 "(1) public education programs, services, and
- demonstrations which are designed to increase gen-
- eral awareness of stillbirths; and
- 19 "(2) the development of tools for the education
- of health professionals and women concerning the
- 21 known risk factors for stillbirth, promotion of fetal
- 22 movement awareness, and the importance of early
- and regular prenatal care to monitor the health and
- development of the fetus up to and during delivery.

- 1 "(g) Task Force.—The Secretary, in consultation
- 2 with the Director of the National Institutes of Health, the
- 3 Director of the Centers for Disease Control and Preven-
- 4 tion, and health care providers, researchers, parents, and
- 5 other groups deemed necessary by the Directors, shall es-
- 6 tablish a task force to develop a national research plan
- 7 to determine the causes of, and how to prevent, stillbirth.
- 8 "(h) Grants for Support Services.—
- 9 "(1) IN GENERAL.—The Secretary, acting 10 through the Administrator of the Health Resources 11 and Services Administration, shall award grants to 12 national organizations, State and local health de-13 partments, and community-based organizations, for 14 the provisions of support services to families who 15 have experienced stillbirth.
 - "(2) APPLICATION.—To be eligible to receive a grant under subsection (a), an entity shall submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require.
 - "(3) USE OF FUNDS.—Amounts received under a grant awarded under subsection (a) may be used to provide grief counseling, education, home visits, 24-hour hotlines, and support groups for families who have experienced stillbirth.

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"(4) Preference.—In awarding grants under subsection (a), the Secretary shall give preference to applicants that are community-based organizations that have a proven history of providing effective direct support services and interventions related to stillbirths and can demonstrate experience through collaborations and partnerships for delivering services throughout a State or region.

"(i) Definitions.—In this section:

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- "(1) The term 'State' has the meaning given to such term in section 2, except that such term includes tribes and tribal organizations (as such terms are defined in section 4 of the Indian Self-Determination and Education Assistance Act).
- "(2) The term 'stillbirth' means a spontaneous, not induced, pregnancy loss 20 weeks or later after gestation, or if the age of the fetus is not known, then a fetus weighing 350 grams or more.
- 19 "(j) AUTHORIZATION OF APPROPRIATIONS.—There 20 is authorized to be appropriated to carry out this section,
- 21 \$3,000,000 for each of fiscal years 2012 through 2016.".

22 SEC. 5. REPORT TO CONGRESS.

- Not later than 2 years after the date of enactment of this Act, the Secretary of Health and Human Services,
- 25 acting through the Director of the Centers for Disease

- 1 Control and Prevention and in consultation with the Di-
- 2 rector of the National Institutes of Health and the Admin-
- 3 istrator of the Health Resources and Services Administra-
- 4 tion, shall submit to Congress a report describing the
- 5 progress made in implementing this Act (and the amend-

6 ments made by this Act).

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