

**(c) Performance measures**

The Secretary shall establish needs indicators and performance measures to evaluate the activities carried out under grants awarded under this section. Such indicators shall be commensurate with national measures of maternal and child health programs and shall be developed in consultation with the Director of the Centers for Disease Control and Prevention.

**(d) Authorization of appropriations**

There are authorized to be appropriated to carry out this section such sums as may be necessary for each of the fiscal years 2001 through 2005.

(July 1, 1944, ch. 373, title III, §317O, as added Pub. L. 106-310, div. A, title XXV, §2502(a), Oct. 17, 2000, 114 Stat. 1162.)

## REFERENCES IN TEXT

The Social Security Act, referred to in subsec. (b)(1), (2)(A), is act Aug. 14, 1935, ch. 531, 49 Stat. 620, as amended. Parts B and E of title IV of the Act are classified generally to parts B (§620 et seq.) and E (§670 et seq.), respectively, of subchapter IV of chapter 7 of this title. Titles V, XIX, and XXI of the Act are classified generally to subchapters V (§701 et seq.), XIX (§1396 et seq.), and XXI (§1397aa et seq.), respectively, of chapter 7 of this title. For complete classification of this Act to the Code, see section 1305 of this title and Tables.

The Head Start Act, referred to in subsec. (b)(2)(B), is subchapter B (§§635-657) of chapter 8 of subtitle A of title VI of Pub. L. 97-35, Aug. 13, 1981, 95 Stat. 499, as amended, which is classified generally to subchapter II (§9831 et seq.) of chapter 105 of this title. For complete classification of this Act to the Code, see Short Title note set out under section 9801 of this title and Tables.

**§ 247b-17. Human papillomavirus (Johanna's Law)****(a) Surveillance****(1) In general**

The Secretary, acting through the Centers for Disease Control and Prevention, shall—

(A) enter into cooperative agreements with States and other entities to conduct sentinel surveillance or other special studies that would determine the prevalence in various age groups and populations of specific types of human papillomavirus (referred to in this section as "HPV") in different sites in various regions of the United States, through collection of special specimens for HPV using a variety of laboratory-based testing and diagnostic tools; and

(B) develop and analyze data from the HPV sentinel surveillance system described in subparagraph (A).

**(2) Report**

The Secretary shall make a progress report to the Congress with respect to paragraph (1) no later than 1 year after the effective date of this section.

**(b) Prevention activities; education program****(1) In general**

The Secretary, acting through the Centers for Disease Control and Prevention, shall conduct prevention research on HPV, including—

(A) behavioral and other research on the impact of HPV-related diagnosis on individuals;

(B) formative research to assist with the development of educational messages and information for the public, for patients, and for their partners about HPV;

(C) surveys of physician and public knowledge, attitudes, and practices about genital HPV infection; and

(D) upon the completion of and based on the findings under subparagraphs (A) through (C), develop and disseminate educational materials for the public and health care providers regarding HPV and its impact and prevention.

**(2) Report; final proposal**

The Secretary shall make a progress report to the Congress with respect to paragraph (1) not later than 1 year after the effective date of this section, and shall develop a final report not later than 3 years after such effective date, including a detailed summary of the significant findings and problems and the best strategies to prevent future infections, based on available science.

**(c) HPV education and prevention****(1) In general**

The Secretary shall prepare and distribute educational materials for health care providers and the public that include information on HPV. Such materials shall address—

(A) modes of transmission;

(B) consequences of infection, including the link between HPV and cervical cancer;

(C) the available scientific evidence on the effectiveness or lack of effectiveness of condoms in preventing infection with HPV; and

(D) the importance of regular Pap smears, and other diagnostics for early intervention and prevention of cervical cancer purposes in preventing cervical cancer.

**(2) Medically accurate information**

Educational material under paragraph (1), and all other relevant educational and prevention materials prepared and printed from this date forward for the public and health care providers by the Secretary (including materials prepared through the Food and Drug Administration, the Centers for Disease Control and Prevention, and the Health Resources and Services Administration), or by contractors, grantees, or subgrantees thereof, that are specifically designed to address STDs including HPV shall contain medically accurate information regarding the effectiveness or lack of effectiveness of condoms in preventing the STD the materials are designed to address. Such requirement only applies to materials mass produced for the public and health care providers, and not to routine communications.

**(d) Johanna's Law****(1) National public awareness campaign****(A) In general**

The Secretary shall carry out a national campaign to increase the awareness and knowledge of health care providers and women with respect to gynecologic cancers.

**(B) Written materials**

Activities under the national campaign under subparagraph (A) shall include—

(i) maintaining a supply of written materials that provide information to the public on gynecologic cancers; and

(ii) distributing the materials to members of the public upon request.

**(C) Public service announcements**

Activities under the national campaign under subparagraph (A) shall, in accordance with applicable law and regulations, include developing and placing, in telecommunications media, public service announcements intended to encourage women to discuss with their physicians their risks of gynecologic cancers. Such announcements shall inform the public on the manner in which the written materials referred to in subparagraph (B) can be obtained upon request, and shall call attention to early warning signs and risk factors based on the best available medical information.

**(2) Report and strategy**

**(A) Report**

Not later than 6 months after January 12, 2007, the Secretary shall submit to the Congress a report including the following:

(i) A description of the past and present activities of the Department of Health and Human Services to increase awareness and knowledge of the public with respect to different types of cancer, including gynecologic cancers.

(ii) A description of the past and present activities of the Department of Health and Human Services to increase awareness and knowledge of health care providers with respect to different types of cancer, including gynecologic cancers.

(iii) For each activity described pursuant to clause (i) or (ii), a description of the following:

(I) The funding for such activity for fiscal year 2006 and the cumulative funding for such activity for previous fiscal years.

(II) The background and history of such activity, including—

(aa) the goals of such activity;

(bb) the communications objectives of such activity;

(cc) the identity of each agency within the Department of Health and Human Services responsible for any aspect of the activity; and

(dd) how such activity is or was expected to result in change.

(III) How long the activity lasted or is expected to last.

(IV) The outcomes observed and the evaluation methods, if any, that have been, are being, or will be used with respect to such activity.

(V) For each such outcome or evaluation method, a description of the associated results, analyses, and conclusions.

**(B) Strategy**

**(i) Development; submission to Congress**

Not later than 3 months after submitting the report required by subparagraph (A),

the Secretary shall develop and submit to the Congress a strategy for improving efforts to increase awareness and knowledge of the public and health care providers with respect to different types of cancer, including gynecological cancers.

**(ii) Consultation**

In developing the strategy under clause (i), the Secretary should consult with qualified private sector groups, including nonprofit organizations.

**(3) Full compliance**

(A) IN GENERAL.—Not later than March 1, 2008, the Secretary shall ensure that all provisions of this section, including activities directed to be carried out by the Centers for Disease Control and Prevention and the Food and Drug Administration, are fully implemented and being complied with. Not later than April 30, 2008, the Secretary shall submit to Congress a report that certifies compliance with the preceding sentence and that contains a description of all activities undertaken to achieve such compliance.

(B) If the Secretary fails to submit the certification as provided for under subparagraph (A), the Secretary shall, not later than 3 months after the date on which the report is to be submitted under subparagraph (A), and every 3 months thereafter, submit to Congress an explanation as to why the Secretary has not yet complied with the first sentence of subparagraph (A), a detailed description of all actions undertaken within the month for which the report is being submitted to bring the Secretary into compliance with such sentence, and the anticipated date the Secretary expects to be in full compliance with such sentence.

**(4) Consultation with nonprofit gynecologic cancer organizations**

In carrying out the national campaign under this subsection, the Secretary shall consult with nonprofit gynecologic cancer organizations, with a mission both to conquer ovarian or other gynecologic cancer and to provide outreach to State and local governments and communities, for the purpose of determining the best practices for providing gynecologic cancer information and outreach services to varied populations.

**(6)<sup>1</sup> Authorization of appropriations**

For the purpose of carrying out this subsection, there is authorized to be appropriated \$16,500,000 for the period of fiscal years 2007 through 2009 and \$18,000,000 for the period of fiscal years 2012 through 2014.

(July 1, 1944, ch. 373, title III, §317P, as added Pub. L. 106-554, §1(a)(1) [title V, §516(a)], Dec. 21, 2000, 114 Stat. 2763, 2763A-72; amended Pub. L. 109-475, §2, Jan. 12, 2007, 120 Stat. 3565; Pub. L. 111-324, §1, Dec. 22, 2010, 124 Stat. 3536.)

REFERENCES IN TEXT

Johanna's Law, referred to in section catchline and subsec. (d), is Pub. L. 109-475, Jan. 12, 2007, 120 Stat.

<sup>1</sup> So in original. No par. (5) has been enacted.

3565, also known as the Gynecologic Cancer Education and Awareness Act of 2005, which amended this section. For complete classification of this Act to the Code, see Short Title of 2007 Amendment note set out under section 201 of this title and Tables.

The effective date of this section, referred to in subsecs. (a)(2) and (b)(2), is the date of enactment of Pub. L. 106-554, which was approved Dec. 21, 2000.

#### AMENDMENTS

2010—Subsec. (d)(4). Pub. L. 111-324, §1(b), added par. (4). Former par. (4) redesignated (6).

Pub. L. 111-324, §1(a)(1), inserted “and \$18,000,000 for the period of fiscal years 2012 through 2014” after “2009”.

Subsec. (d)(6). Pub. L. 111-324, §1(a)(2), redesignated par. (4) as (6).

2007—Pub. L. 109-475, §2(1), inserted “(Johanna’s Law)” after “papillomavirus” in section catchline.

Subsec. (d). Pub. L. 109-475, §2(2), added subsec. (d).

### § 247b-18. Surveillance and research regarding muscular dystrophy

#### (a) In general

The Secretary, acting through the Director of the Centers for Disease Control and Prevention, may award grants and cooperative agreements to public or nonprofit private entities (including health departments of States and political subdivisions of States, and including universities and other educational entities) for the collection, analysis, and reporting of data on Duchenne and other forms of muscular dystrophy. In making such awards, the Secretary may provide direct technical assistance in lieu of cash.

#### (b) National muscular dystrophy epidemiology program

The Secretary, acting through the Director of the Centers for Disease Control and Prevention, may award grants to public or nonprofit private entities (including health departments of States and political subdivisions of States, and including universities and other educational entities) for the purpose of carrying out epidemiological activities regarding Duchenne and other forms of muscular dystrophies, including collecting and analyzing information on the number, incidence, correlates, and symptoms of cases. In carrying out the preceding sentence, the Secretary shall provide for a national surveillance program and, to the extent possible, ensure that data be representative of all affected populations and shared in a timely manner. In making awards under this subsection, the Secretary may provide direct technical assistance in lieu of cash.

#### (c) Coordination with centers of excellence

The Secretary shall ensure that epidemiological information under subsections (a) and (b) is made available to centers of excellence supported under section 283g(b) of this title by the Director of the National Institutes of Health.

#### (d) Data

In carrying out this section, the Secretary may ensure that any data on patients that is collected as part of the Muscular Dystrophy STARnet (under a grant under this section) is regularly updated to reflect changes in patient condition over time.

#### (e) Reports and study

##### (1) Annual report

Not later than 18 months after October 8, 2008, and annually thereafter, the Director of the Centers for Disease Control and Prevention shall submit to the appropriate committees of the Congress a report—

(A) concerning the activities carried out by MD STARnet site<sup>1</sup> funded under this section during the year for which the report is prepared;

(B) concerning the data collected and findings derived from the MD STARnet sites each fiscal year (as funded under a grant under this section during fiscal years 2008 through 2012); and

(C) that every 2 years outlines prospective data collection objectives and strategies.

##### (2) Tracking health outcomes

The Secretary may provide health outcome data on the health and survival of people with muscular dystrophy.

#### (f) Authorization of appropriations

There are authorized to be appropriated such sums as may be necessary to carry out this section.

(July 1, 1944, ch. 373, title III, §317Q, as added Pub. L. 107-84, §4, Dec. 18, 2001, 115 Stat. 828; amended Pub. L. 110-361, §3, Oct. 8, 2008, 122 Stat. 4010; Pub. L. 113-166, §3, Sept. 26, 2014, 128 Stat. 1880.)

#### AMENDMENTS

2014—Subsec. (b). Pub. L. 113-166 inserted “and, to the extent possible, ensure that data be representative of all affected populations and shared in a timely manner” after “surveillance program”.

2008—Subsecs. (d) to (f). Pub. L. 110-361 added subsecs. (d) and (e) and redesignated former subsec. (d) as (f).

#### FINDINGS

Pub. L. 107-84, §2, Dec. 18, 2001, 115 Stat. 823, provided that: “Congress makes the following findings:

“(1) Of the childhood muscular dystrophies, Duchenne Muscular Dystrophy (DMD) is the world’s most common and catastrophic form of genetic childhood disease, and is characterized by a rapidly progressive muscle weakness that almost always results in death, usually by 20 years of age.

“(2) Duchenne muscular dystrophy is genetically inherited, and mothers are the carriers in approximately 70 percent of all cases.

“(3) If a female is a carrier of the dystrophin gene, there is a 50 percent chance per birth that her male offspring will have Duchenne muscular dystrophy, and a 50 percent chance per birth that her female offspring will be carriers.

“(4) Duchenne is the most common lethal genetic disorder of childhood worldwide, affecting approximately 1 in every 3,500 boys worldwide.

“(5) Children with muscular dystrophy exhibit extreme symptoms of weakness, delay in walking, waddling gait, difficulty in climbing stairs, and progressive mobility problems often in combination with muscle hypertrophy.

“(6) Other forms of muscular dystrophy affecting children and adults include Becker, limb girdle, congenital, facioscapulohumeral, myotonic, oculopharyngeal, distal, and Emery-Dreifuss muscular dystrophies.

<sup>1</sup> So in original. Probably should be plural.