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[1] funded under this section during the year for which the report is prepared;

(B) containing 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.

[1] So in original. Probably should be plural.

''(7) Myotonic muscular dystrophy (also known as Steinert's disease and dystrophia myotonica) is the second most prominent form of muscular dystrophy and the type most commonly found in adults. Unlike any of the other muscular dystrophies, the muscle weakness is accompanied by myotonia (delayed relaxation of muscles after contraction) and by a variety of abnormalities in addition to those of muscle.

''(8) Facioscapulohumeral muscular dystrophy (referred to in this section as 'FSHD') is a neuromuscular disorder that is inherited genetically and has an estimated frequency of 1 in 20,000. FSHD, affecting between 15,000 to 40,000 persons, causes a progressive and sever [sic] loss of skeletal muscle gradually bringing weakness and reduced mobility. Many persons with FSHD become severely physically disabled and spend many decades in a wheelchair.

''(9) FSHD is regarded as a novel genetic phenomenon resulting from a crossover of subtelomeric DNA and may be the only human disease caused by a deletion-mutation.

''(10) Each of the muscular dystrophies, though distinct in progressivity and severity of symptoms, have a devastating impact on tens of thousands of children and adults throughout the United States and worldwide and impose severe physical and economic burdens on those affected.

''(11) Muscular dystrophies have a significant impact on quality of life—not only for the individual who experiences its painful symptoms and resulting disability, but also for family members and caregivers.

''(12) Development of therapies for these disorders, while realistic with recent advances in research, is likely to require costly investments and infrastructure to support gene and other therapies.

''(13) There is a shortage of qualified researchers in the field of neuromuscular research.

''(14) Many family physicians and health care professionals lack the knowledge and resources to detect and properly diagnose the disease as early as possible, thus exacerbating the progressiveness of symptoms in cases that go undetected or misdiagnosed.

''(15) There is a need for efficient mechanisms to translate clinically relevant findings in muscular dystrophy research from basic science to applied work.

''(16) Educating the public and health care community throughout the country about this devastating disease is of paramount importance and is in every respect in the public interest and to the benefit of all communities.''

REPORT TO CONGRESS

Pub. L. 107–84, § 6, Dec. 18, 2001, 115 Stat. 829, which directed the Secretary of Health and Human Services to prepare and submit to appropriate committees of Congress a report concerning the implementation of Pub. L. 107–84 not later than Jan. 1, 2003, and each Jan. 1 thereafter, was repealed by Pub. L. 109–482, title I, § 104(b)(3)(H), Jan. 15, 2007, 120 Stat. 3694.

§ 247b–19. Information and education

(a) In general

The Secretary of Health and Human Services (referred to in this Act as the ''Secretary'') shall establish and implement a program to provide information and education on muscular dystrophy to health professionals and the general public, including information and education on advances in the diagnosis and treatment of muscular dystrophy and training and continuing education through programs for scientists, physicians, medical students, and other health professionals who provide care for patients with muscular dystrophy.

(b) Stipends

The Secretary may use amounts made available under this section provides[1] stipends for health professionals who are enrolled in training programs under this section.

(c) Requirements

In carrying out this section, the Secretary may—

(1) partner with leaders in the muscular dystrophy patient community;

(2) cooperate with professional organizations and the patient community in the development and issuance of care considerations for pediatric and adult patients, including acute care considerations, for Duchenne-Becker muscular dystrophy, and various other forms of muscular dystrophy, and in periodic review and updates, as appropriate;

(3) in developing and updating care considerations under paragraph (2), incorporate strategies specifically responding to the findings of the national transitions survey of minority, young adult, and adult communities of muscular dystrophy patients; and

(4) widely disseminate the Duchenne-Becker muscular dystrophy and various other forms of muscular dystrophy care considerations as broadly as possible, including through partnership opportunities with the muscular dystrophy patient community.

(d) Authorization of appropriations

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

(Pub. L. 107–84, § 5, Dec. 18, 2001, 115 Stat. 828; Pub. L. 110–361, § 4, Oct. 8, 2008, 122 Stat. 4011; Pub. L. 113–166, § 4, Sept. 26, 2014, 128 Stat. 1880.)

REFERENCES IN TEXT

This Act, referred to in subsec. (a), is Pub. L. 107–84, Dec. 18, 2001, 115 Stat. 823, known as the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 and also as the MD–CARE Act. For complete classification of this Act to the Code, see Short Title of 2001 Amendment note set out under section 201 of this title and Tables.

CODIFICATION

Section was enacted as part of the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001, also known as the MD–CARE Act, and not as part of the Public Health Service Act which comprises this chapter.

AMENDMENTS

2014—Subsec. (c)(2). Pub. L. 113–166, § 4(1), inserted ''for pediatric and adult patients, including acute care considerations,'' after ''issuance of care considerations'' and ''various'' before ''other forms of muscular dystrophy'' and struck out ''and'' at end.

Subsec. (c)(3), (4). Pub. L. 113–166, § 4(2)–(4), added par. (3), redesignated former par. (3) as (4), and, in par. (4), inserted ''various'' before ''other forms of muscular dystrophy''.

2008—Subsecs. (c), (d). Pub. L. 110–361 added subsec. (c) and redesignated former subsec. (c) as (d).

§ 247b–20. Food safety grants

(a) In general

The Secretary may award grants to States and Indian tribes (as defined in section 5304(e) of

[1] So in original. Probably should be ''to provide''.