

“(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 severe [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<sup>1</sup> 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

<sup>1</sup> So in original. Probably should be “to provide”.