

One Hundred Tenth Congress
of the
United States of America

AT THE SECOND SESSION

*Begun and held at the City of Washington on Thursday,
the third day of January, two thousand and eight*

An Act

To amend the Public Health Service Act to provide for research with respect to various forms of muscular dystrophy, including Becker, congenital, distal, Duchenne, Emery-Dreifuss facioscapulohumeral, limb-girdle, myotonic, and oculopharyngeal, muscular dystrophies.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the “Paul D. Wellstone Muscular Dystrophy Community Assistance, Research, and Education Amendments of 2008”.

SEC. 2. EXPANSION, INTENSIFICATION, AND COORDINATION OF ACTIVITIES OF NIH WITH RESPECT TO RESEARCH ON MUSCULAR DYSTROPHY.

(a) TECHNICAL CORRECTION.—Section 404E of the Public Health Service Act (42 U.S.C. 283g) is amended by striking subsection (f) (relating to reports to Congress) and redesignating subsection (g) as subsection (f).

(b) AMENDMENTS.—Section 404E of the Public Health Service Act (42 U.S.C. 283g) is amended—

(1) in subsection (a)(1), by inserting “the National Heart, Lung, and Blood Institute,” after “the Eunice Kennedy Shriver National Institute of Child Health and Human Development,”;

(2) in subsection (b)(1), by adding at the end of the following: “Such centers of excellence shall be known as the ‘Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers’”; and

(3) by adding at the end the following:

“(g) CLINICAL RESEARCH.—The Coordinating Committee may evaluate the potential need to enhance the clinical research infrastructure required to test emerging therapies for the various forms of muscular dystrophy by prioritizing the achievement of the goals related to this topic in the plan under subsection (e)(1).”.

SEC. 3. DEVELOPMENT AND EXPANSION OF ACTIVITIES OF CDC WITH RESPECT TO EPIDEMIOLOGICAL RESEARCH ON MUSCULAR DYSTROPHY.

Section 317Q of the Public Health Service Act (42 U.S.C. 247b-18) is amended—

(1) by redesignating subsection (d) as subsection (f); and

(2) by inserting after subsection (c) the following:

“(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 the date of the enactment of the Paul D. Wellstone Muscular Dystrophy Community Assistance, Research, and Education Amendments of 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 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.”.

SEC. 4. INFORMATION AND EDUCATION.

Section 5 of the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 (42 U.S.C. 247b-19) is amended—

“(1) by redesignating subsection (c) as subsection (d); and
“(2) by inserting after subsection (b) the following:

“(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 Duchenne-Becker muscular dystrophy, and other forms of muscular dystrophy, and in periodic review and updates, as appropriate; and

“(3) widely disseminate the Duchenne-Becker muscular dystrophy and other forms of muscular dystrophy care considerations as broadly as possible, including through partnership

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opportunities with the muscular dystrophy patient community.”.

Speaker of the House of Representatives.

*Vice President of the United States and
President of the Senate.*