

***In the Senate of the United States,***

*September 26 (legislative day, September 17), 2008.*

*Resolved*, That the bill from the House of Representatives (H.R. 5265) entitled “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.”, do pass with the following

**AMENDMENT:**

Strike all after the enacting clause and insert the following:

1 ***SECTION 1. SHORT TITLE.***

2 *This Act may be cited as the “Paul D. Wellstone Mus-*  
3 *cular Dystrophy Community Assistance, Research, and*  
4 *Education Amendments of 2008”.*

1 **SEC. 2. EXPANSION, INTENSIFICATION, AND COORDINA-**  
2 **TION OF ACTIVITIES OF NIH WITH RESPECT**  
3 **TO RESEARCH ON MUSCULAR DYSTROPHY.**

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

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

10 (1) *in subsection (a)(1), by inserting “the Na-*  
11 *tional Heart, Lung, and Blood Institute,” after “the*  
12 *Eunice Kennedy Shriver National Institute of Child*  
13 *Health and Human Development,”;*

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

18 (3) *by adding at the end the following:*

19 “(g) *CLINICAL RESEARCH.*—*The Coordinating Com-*  
20 *mittee may evaluate the potential need to enhance the clin-*  
21 *ical research infrastructure required to test emerging thera-*  
22 *pies for the various forms of muscular dystrophy by*  
23 *prioritizing the achievement of the goals related to this topic*  
24 *in the plan under subsection (e)(1).”.*

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

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

6 *(1) by redesignating subsection (d) as subsection*  
7 *(f); and*

8 *(2) by inserting after subsection (c) the fol-*  
9 *lowing:*

10 *“(d) DATA.—In carrying out this section, the Sec-*  
11 *retary may ensure that any data on patients that is col-*  
12 *lected as part of the Muscular Dystrophy STARnet (under*  
13 *a grant under this section) is regularly updated to reflect*  
14 *changes in patient condition over time.*

15 *“(e) REPORTS AND STUDY.—*

16 *“(1) ANNUAL REPORT.—Not later than 18*  
17 *months after the date of the enactment of the Paul D.*  
18 *Wellstone Muscular Dystrophy Community Assist-*  
19 *ance, Research, and Education Amendments of 2008,*  
20 *and annually thereafter, the Director of the Centers*  
21 *for Disease Control and Prevention shall submit to*  
22 *the appropriate committees of the Congress a report—*

23 *“(A) concerning the activities carried out by*  
24 *MD STARnet site funded under this section dur-*  
25 *ing the year for which the report is prepared;*

1           “(B) containing the data collected and find-  
2           ings derived from the MD STARnet sites each  
3           fiscal year (as funded under a grant under this  
4           section during fiscal years 2008 through 2012);  
5           and

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

8           “(2) TRACKING HEALTH OUTCOMES.—The Sec-  
9           retary may provide health outcome data on the health  
10          and survival of people with muscular dystrophy.”

11 **SEC. 4. INFORMATION AND EDUCATION.**

12          Section 5 of the Muscular Dystrophy Community As-  
13          sistance, Research and Education Amendments of 2001 (42  
14          U.S.C. 247b–19) is amended—

15                 (1) by redesignating subsection (c) as subsection  
16                 (d); and

17                 (2) by inserting after subsection (b) the fol-  
18                 lowing:

19                 “(c) REQUIREMENTS.—In carrying out this section,  
20          the Secretary may—

21                         “(1) partner with leaders in the muscular dys-  
22                         trophy patient community;

23                         “(2) cooperate with professional organizations  
24                         and the patient community in the development and  
25                         issuance of care considerations for Duchenne-Becker

1     *muscular dystrophy, and other forms of muscular*  
2     *dystrophy, and in periodic review and updates, as*  
3     *appropriate; and*

4             *“(3) widely disseminate the Duchenne-Becker*  
5     *muscular dystrophy and other forms of muscular dys-*  
6     *trophy care considerations as broadly as possible, in-*  
7     *cluding through partnership opportunities with the*  
8     *muscular dystrophy patient community.”.*

Attest:

*Secretary.*

110<sup>TH</sup> CONGRESS  
2<sup>D</sup> SESSION

**H.R. 5265**

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**AMENDMENT**