

113TH CONGRESS
1ST SESSION

S. 315

To reauthorize and extend the Paul D. Wellstone Muscular Dystrophy Community Assistance, Research, and Education Amendments of 2008.

IN THE SENATE OF THE UNITED STATES

FEBRUARY 13, 2013

Ms. KLOBUCHAR (for herself, Mr. WICKER, Mr. SANDERS, Ms. COLLINS, Mr. MENENDEZ, Mr. ISAKSON, Ms. MIKULSKI, Mr. LEAHY, Mr. LAUTENBERG, and Mr. NELSON) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To reauthorize and extend the Paul D. Wellstone Muscular Dystrophy Community Assistance, Research, and Education Amendments of 2008.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Paul D. Wellstone
5 Muscular Dystrophy Community Assistance, Research and
6 Education (MD-CARE) Amendments of 2013”.

1 **SEC. 2. INITIATIVE THROUGH THE DIRECTOR OF THE NA-**
2 **TIONAL INSTITUTES OF HEALTH.**

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

5 (1) in subsection (a)(1)—

6 (A) by striking “Muscoskeletal” and in-
7 serting “Musculoskeletal”; and

8 (B) by inserting “Becker, myotonic,
9 facioscapulohumeral muscular dystrophy (re-
10 ferred to in this section as ‘FSHD’), Congenital
11 muscular dystrophy, Limb-girdle muscular dys-
12 trophy,” after “Duchenne,”;

13 (2) in subsection (b)—

14 (A) in paragraph (2), by inserting “cardiac
15 and pulmonary function,” after “imaging, ge-
16 netics,”; and

17 (B) in paragraph (3), by inserting “and
18 sharing of data” after “regular communica-
19 tion”;

20 (3) in subsection (d)—

21 (A) in paragraph (2)—

22 (i) in the matter preceding subpara-
23 graph (A), by striking “15” and inserting
24 “18”; and

25 (ii) in subparagraph (A), by striking
26 “children with muscular dystrophy, such as

1 the Department of Education” and insert-
2 ing “children and adults with muscular
3 dystrophy, such as the Department of
4 Education, the Social Security Administra-
5 tion, the United States Administration for
6 Community Living”; and

7 (B) in paragraph (4)(B), by inserting “,
8 and shall meet no less than two times per cal-
9 endar year” before the period;

10 (4) in subsection (e)—

11 (A) in paragraph (1)—

12 (i) in the matter preceding subpara-
13 graph (A), by striking “through the na-
14 tional research institutes” and inserting
15 “through the represented Federal agen-
16 cies”; and

17 (ii) in subparagraph (A), by striking
18 “and rehabilitative issues, including studies
19 of the impact of such diseases in rural and
20 underserved communities” and inserting
21 “public resources, and rehabilitative issues,
22 including studies of the impact of such dis-
23 eases in rural and underserved commu-
24 nities, health economic studies to dem-
25 onstrate the cost-effectiveness of providing

1 independent living resources and support
2 to patients with various forms of muscular
3 dystrophy, and studies to determine opti-
4 mal clinical care interventions for adults
5 with various forms of muscular dys-
6 trophy”; and

7 (B) in paragraph (2), by adding at the end
8 the following:

9 “(F) The development of clinical interven-
10 tions to improve the health of adults with var-
11 ious forms of muscular dystrophy.”; and

12 (5) in subsection (g), by striking “for the var-
13 ious forms of muscular dystrophy by prioritizing the
14 achievement of the goals related to this topic in the
15 plan under subsection (e)(1)” and inserting “and
16 shall, not later than 6 months after the date of en-
17 actment of the Paul D. Wellstone Muscular Dys-
18 trophy Community Assistance, Research and Edu-
19 cation (MD-CARE) Amendments of 2013, in coordi-
20 nation with appropriate Federal agencies, including
21 relevant offices within the Food and Drug Adminis-
22 tration and supported by the National Institutes of
23 Health and Department of Defense, develop a plan
24 to expedite the evaluation and approval of emerging
25 therapies and personalized medicines that have the

1 potential to decrease fatal disease progression across
2 the various forms of muscular dystrophy”.

3 **SEC. 3. SURVEILLANCE AND RESEARCH REGARDING MUS-**
4 **CULAR DYSTROPHY.**

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

7 (1) in the second sentence of subsection (b), by
8 inserting before the period the following: “and en-
9 sure that the program captures data from different
10 racial and ethnic populations, and that such data
11 are made publicly available to investigators con-
12 ducting public or private research on muscular dys-
13 trophy”; and

14 (2) in subsection (c), by adding at the end the
15 following: “The Secretary shall also foster ongoing
16 engagement and collaboration between the surveil-
17 lance program and centers of excellence.”.

18 **SEC. 4. INFORMATION AND EDUCATION.**

19 Section 5(c) of the Muscular Dystrophy Community
20 Assistance, Research and Education Amendments of 2001
21 (42 U.S.C. 247b–19(c)) is amended by adding at the end
22 the following:

23 “(4) Update and widely disseminate existing
24 Duchenne-Becker muscular dystrophy care consider-
25 ations for pediatric patients, develop and widely dis-

1 seminate Duchenne-Becker muscular dystrophy care
2 considerations for adult patients, and develop and
3 widely disseminate acute care considerations for all
4 muscular dystrophy populations. The care consider-
5 ations should build upon existing efforts currently
6 underway for congenital muscular dystrophy,
7 fascioscapulohumeral muscular dystrophy, limb-gir-
8 dle muscular dystrophy, and myotonic muscular dys-
9 trophy, and incorporate strategies specifically re-
10 sponding to the findings of the national transitions
11 survey of minority, young adult and adult commu-
12 nities of muscular dystrophy patients.”.

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