

AMENDMENT NO. _____ Calendar No. _____

Purpose: In the nature of a substitute.

IN THE SENATE OF THE UNITED STATES—113th Cong., 2d Sess.

S. 315

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

Referred to the Committee on _____ and
ordered to be printed

Ordered to lie on the table and to be printed

Amendments In the Nature of a Substitute intended to be
proposed by _____

Viz:

1 Strike all after the enacting clause and insert the fol-
2 lowing:

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 Amendments of 2014”.

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

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

11 (1) in subsection (a)(1)—

1 (A) by striking “Muscoskeletal” and in-
2 serting “Musculoskeletal”; and

3 (B) by inserting “Becker, congenital mus-
4 cular dystrophy, limb-girdle muscular dys-
5 trophy,” after “Duchenne,”;

6 (2) in subsection (b)—

7 (A) in paragraph (2)—

8 (i) by striking “genetics,” at the sec-
9 ond place it appears; and

10 (ii) by inserting “cardiac and pul-
11 monary function, and” after “imaging,”;
12 and

13 (B) in paragraph (3), by inserting “and
14 sharing of data” after “regular communica-
15 tion”;

16 (3) in subsection (d)—

17 (A) in paragraph (2)—

18 (i) in the matter preceding subpara-
19 graph (A), by striking “15” and inserting
20 “18”; and

21 (ii) in subparagraph (A)—

22 (I) by striking “and the Food
23 and Drug Administration” and insert-
24 ing “, the Food and Drug Administra-

1 tion, and the Administration for Com-
2 munity Living”;

3 (II) by inserting “and adults”
4 after “children”; and

5 (III) by striking “such as the De-
6 partment of Education” and inserting
7 “including the Department of Edu-
8 cation and the Social Security Admin-
9 istration”; and

10 (B) in paragraph (4)(B), by inserting “,
11 but shall meet no fewer than two times per cal-
12 endar year” before the period; and

13 (4) in subsection (e)—

14 (A) in paragraph (1)—

15 (i) in the matter preceding subpara-
16 graph (A), by striking “through the na-
17 tional research institutes” and inserting
18 “through the agencies represented on the
19 Coordinating Committee pursuant to sub-
20 section (d)(2)(A)”; and

21 (ii) in subparagraph (A)—

22 (I) by inserting “public services,”
23 before “and rehabilitative issues”; and

24 (II) by inserting “, studies to
25 demonstrate the cost-effectiveness of

1 providing independent living resources
2 and support to patients with various
3 forms of muscular dystrophy, and
4 studies to determine optimal clinical
5 care interventions for adults with var-
6 ious forms of muscular dystrophy”
7 after “including studies of the impact
8 of such diseases in rural and under-
9 served communities”; and

10 (B) in paragraph (2)(D), by inserting after
11 “including new biological agents” the following:
12 “and new clinical interventions to improve the
13 health of those with muscular dystrophy”.

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

16 The second sentence of section 317Q(b) of the Public
17 Health Service Act (42 U.S.C. 247b–18(b)) is amended
18 by inserting before the period the following: “and, to the
19 extent possible, ensure that data be representative of all
20 affected populations and shared in a timely manner”.

21 **SEC. 4. INFORMATION AND EDUCATION.**

22 Section 5(c) of the Muscular Dystrophy Community
23 Assistance, Research and Education Amendments of 2001
24 (42 U.S.C. 247b–19(c)) is amended—

25 (1) in paragraph (2)—

1 (A) by inserting “for pediatric and adult
2 patients, including acute care considerations,”
3 after “issuance of care considerations”;

4 (B) by inserting “various” before “other
5 forms of muscular dystrophy”; and

6 (C) by striking “and” at the end;

7 (2) by redesignating paragraph (3) as para-
8 graph (4);

9 (3) by inserting after paragraph (2) the fol-
10 lowing:

11 “(3) in developing and updating care consider-
12 ations under paragraph (2), incorporate strategies
13 specifically responding to the findings of the national
14 transitions survey of minority, young adult, and
15 adult communities of muscular dystrophy patients;
16 and”; and

17 (4) in paragraph (4), as redesignated, by insert-
18 ing “various” before “other forms of muscular dys-
19 trophy”.

Amend the title so as to read: “A bill to amend the
Public Health Service Act relating to Federal research on
muscular dystrophy, and for other purposes.”.