

**AMENDMENT IN THE NATURE OF A SUBSTITUTE
TO H.R. 594
OFFERED BY M . _____**

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
3 Muscular Dystrophy Community Assistance, Research and
4 Education Amendments of 2014”.

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

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

9 (1) in subsection (a)(1)—

10 (A) by striking “Muscoskeletal” and in-
11 serting “Musculoskeletal”; and

12 (B) by inserting “Becker, congenital mus-
13 cular dystrophy, limb-girdle muscular dys-
14 trophy,” after “Duchenne,”;

15 (2) in subsection (b)—

16 (A) in paragraph (2)—

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

1 (ii) by inserting “cardiac and pul-
2 monary function, and” after “imaging,”;
3 and

4 (B) in paragraph (3), by inserting “and
5 sharing of data” after “regular communica-
6 tion”;

7 (3) in subsection (d)—

8 (A) in paragraph (2)—

9 (i) in the matter preceding subpara-
10 graph (A), by striking “15” and inserting
11 “18”; and

12 (ii) in subparagraph (A)—

13 (I) by striking “and the Food
14 and Drug Administration” and insert-
15 ing “, the Food and Drug Administra-
16 tion, and the Administration for Com-
17 munity Living”;

18 (II) by inserting “and adults”
19 after “children”; and

20 (III) by striking “such as the De-
21 partment of Education” and inserting
22 “including the Department of Edu-
23 cation and the Social Security Admin-
24 istration”; and

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

4 (4) in subsection (e)—

5 (A) in paragraph (1)—

6 (i) in the matter preceding subpara-
7 graph (A), by striking “through the na-
8 tional research institutes” and inserting
9 “through the agencies represented on the
10 Coordinating Committee pursuant to sub-
11 section (d)(2)(A)”;

12 (ii) in subparagraph (A)—

13 (I) by inserting “public services,”
14 before “and rehabilitative issues”; and

15 (II) by inserting “, health eco-
16 nomic studies to demonstrate the cost-
17 effectiveness of providing independent
18 living resources and support to pa-
19 tients with various forms of muscular
20 dystrophy, and studies to determine
21 optimal clinical care interventions for
22 adults with various forms of muscular
23 dystrophy” after “including studies of
24 the impact of such diseases in rural
25 and underserved communities”; and

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

3 “(F) The development of clinical interven-
4 tions to improve the health of adults with var-
5 ious forms of muscular dystrophy.”

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

8 The second sentence of section 317Q(b) of the Public
9 Health Service Act (42 U.S.C. 247b–18(b)) is amended
10 by inserting before the period the following: “and ensure
11 that the program captures data from different racial and
12 ethnic populations, and that such data are made publicly
13 available to investigators conducting public or private re-
14 search on muscular dystrophy”.

15 **SEC. 4. INFORMATION AND EDUCATION.**

16 Section 5(c) of the Muscular Dystrophy Community
17 Assistance, Research and Education Amendments of 2001
18 (42 U.S.C. 247b–19(c)) is amended—

19 (1) in paragraph (2)—

20 (A) by inserting “for pediatric and adult
21 patients, including acute care considerations,”
22 after “issuance of care considerations”;

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

25 (C) by striking “and” at the end;

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

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

5 “(3) in developing and updating care consider-
6 ations under paragraph (2), incorporate strategies
7 specifically responding to the findings of the national
8 transitions survey of minority, young adult, and
9 adult communities of muscular dystrophy patients;
10 and”;

11 (4) in paragraph (4), as redesignated, by insert-
12 ing “various” before “other forms of muscular dys-
13 trophy”.

Amend the long title to read as follows: “To amend the Public Health Service Act relating to Federal research on muscular dystrophy, and other purposes.”.

