

Union Calendar No.

113TH CONGRESS
2^D SESSION

H. R. 594

[Report No. 113-]

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

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 8, 2013

Mr. BURGESS (for himself and Mr. ENGEL) introduced the following bill;
which was referred to the Committee on Energy and Commerce

JULY --, 2014

Reported with amendments, committed to the Committee of the Whole House
on the State of the Union, and ordered to be printed

[Strike out all after the enacting clause and insert the part printed in italic]

[For text of introduced bill, see copy of bill as introduced on February 8, 2013]

A BILL

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

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 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 insert-*
11 *ing “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 second*
18 *place it appears; and*

19 *(ii) by inserting “cardiac and pul-*
20 *monary function, and” after “imaging,”;*
21 *and*

22 *(B) in paragraph (3), by inserting “and*
23 *sharing of data” after “regular communication”;*

24 *(3) in subsection (d)—*

25 *(A) in paragraph (2)—*

1 (i) in the matter preceding subpara-
2 graph (A), by striking “15” and inserting
3 “18”; and

4 (ii) in subparagraph (A)—

5 (I) by striking “and the Food and
6 Drug Administration” and inserting “,
7 the Food and Drug Administration,
8 and the Administration for Commu-
9 nity Living”;

10 (II) by inserting “and adults”
11 after “children”; and

12 (III) by striking “such as the De-
13 partment of Education” and inserting
14 “including the Department of Edu-
15 cation and the Social Security Admin-
16 istration”; and

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

20 (4) in subsection (e)—

21 (A) in paragraph (1)—

22 (i) in the matter preceding subpara-
23 graph (A), by striking “through the na-
24 tional research institutes” and inserting
25 “through the agencies represented on the Co-

1 *ordinating Committee pursuant to sub-*
2 *section (d)(2)(A)”; and*

3 *(ii) in subparagraph (A)—*

4 *(I) by inserting “public services,”*
5 *before “and rehabilitative issues”; and*

6 *(II) by inserting “, studies to*
7 *demonstrate the cost-effectiveness of*
8 *providing independent living resources*
9 *and support to patients with various*
10 *forms of muscular dystrophy, and*
11 *studies to determine optimal clinical*
12 *care interventions for adults with var-*
13 *ious forms of muscular dystrophy”*
14 *after “including studies of the impact*
15 *of such diseases in rural and under-*
16 *served communities”; and*

17 *(B) in paragraph (2)(D), by inserting after*
18 *“including new biological agents” the following:*
19 *“and new clinical interventions to improve the*
20 *health of those with muscular dystrophy”.*

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

23 *The second sentence of section 317Q(b) of the Public*
24 *Health Service Act (42 U.S.C. 247b–18(b)) is amended by*
25 *inserting before the period the following: “and, to the extent*

1 *possible, ensure that data be representative of all affected*
2 *populations and shared in a timely manner”.*

3 **SEC. 4. INFORMATION AND EDUCATION.**

4 *Section 5(c) of the Muscular Dystrophy Community*
5 *Assistance, Research and Education Amendments of 2001*
6 *(42 U.S.C. 247b–19(c)) is amended—*

7 *(1) in paragraph (2)—*

8 *(A) by inserting “for pediatric and adult*
9 *patients, including acute care considerations,”*
10 *after “issuance of care considerations”;*

11 *(B) by inserting “various” before “other*
12 *forms of muscular dystrophy”;* and

13 *(C) by striking “and” at the end;*

14 *(2) by redesignating paragraph (3) as para-*
15 *graph (4);*

16 *(3) by inserting after paragraph (2) the fol-*
17 *lowing:*

18 *“(3) in developing and updating care consider-*
19 *ations under paragraph (2), incorporate strategies*
20 *specifically responding to the findings of the national*
21 *transitions survey of minority, young adult, and*
22 *adult communities of muscular dystrophy patients;*
23 *and”;* and

1 (4) *in paragraph (4), as redesignated, by insert-*
2 *ing “various” before “other forms of muscular dys-*
3 *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 other purposes.”.