

COMMITTEE PRINT

[SHOWING H.R. 594, AS FAVORABLY FORWARDED BY THE SUBCOMMITTEE
ON HEALTH ON JUNE 20, 2014]

113TH CONGRESS
1ST SESSION

H. R. 594

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

A BILL

To reauthorize and extend the Paul D. Wellstone Muscular
Dystrophy Community Assistance, Research, and Edu-
cation 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 Amendments of 2014”.

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, congenital mus-
9 cular dystrophy, limb-girdle muscular dys-
10 trophy,” after “Duchenne,”;

11 (2) in subsection (b)—

12 (A) in paragraph (2)—

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

15 (ii) by inserting “cardiac and pul-
16 monary function, and” after “imaging,”;
17 and

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

21 (3) in subsection (d)—

22 (A) in paragraph (2)—

23 (i) in the matter preceding subpara-
24 graph (A), by striking “15” and inserting
25 “18”; and

26 (ii) in subparagraph (A)—

1 (I) by striking “and the Food
2 and Drug Administration” and insert-
3 ing “, the Food and Drug Administra-
4 tion, and the Administration for Com-
5 munity Living”;

6 (II) by inserting “and adults”
7 after “children”; and

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

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

16 (4) in subsection (e)—

17 (A) in paragraph (1)—

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

24 (ii) in subparagraph (A)—

1 (I) by inserting “public services,”
2 before “and rehabilitative issues”; and

3 (II) by inserting “, health eco-
4 nomic studies to demonstrate the cost-
5 effectiveness of providing independent
6 living resources and support to pa-
7 tients with various forms of muscular
8 dystrophy, and studies to determine
9 optimal clinical care interventions for
10 adults with various forms of muscular
11 dystrophy” after “including studies of
12 the impact of such diseases in rural
13 and underserved communities”; and

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

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

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

21 The second sentence of section 317Q(b) of the Public
22 Health Service Act (42 U.S.C. 247b–18(b)) is amended
23 by inserting before the period the following: “and ensure
24 that the program captures data from different racial and
25 ethnic populations, and that such data are made publicly

1 available to investigators conducting public or private re-
2 search on muscular dystrophy”.

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”;

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.”.