

113<sup>TH</sup> CONGRESS  
2<sup>D</sup> SESSION

# H. R. 594

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## AN ACT

To amend the Public Health Service Act relating to Federal research on muscular dystrophy, and for other purposes.

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

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 sserting “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

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 communica-  
24 tion”;

25 (3) in subsection (d)—

26 (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  
6 and Drug Administration” and insert-  
7 ing “, the Food and Drug Administra-  
8 tion, and the Administration for Com-  
9 munity 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

1 Coordinating 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  
25 by inserting before the period the following: “and, to the

1 extent possible, ensure that data be representative of all  
2 affected 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”;

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

Passed the House of Representatives July 28, 2014.

Attest:

*Clerk.*



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