

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.

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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

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## 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 2013”.

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—

1 (1) in subsection (a)(1)—

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

4 (B) by inserting “Becker, myotonic,  
5 facioscapulohumeral muscular dystrophy (re-  
6 ferred to in this section as ‘FSHD’), Congenital  
7 muscular dystrophy, Limb-girdle muscular dys-  
8 trophy,” after “Duchenne,”;

9 (2) in subsection (b)—

10 (A) in paragraph (2), by inserting “cardiac  
11 and pulmonary function,” after “imaging, ge-  
12 netics,”; 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), by striking  
22 “children with muscular dystrophy, such as  
23 the Department of Education” and insert-  
24 ing “children and adults with muscular  
25 dystrophy, such as the Department of

1 Education, the Social Security Administra-  
2 tion, the United States Administration for  
3 Community Living”; and

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

7 (4) in subsection (e)—

8 (A) in paragraph (1)—

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

15 (ii) in subparagraph (A), by striking  
16 “and rehabilitative issues, including studies  
17 of the impact of such diseases in rural and  
18 underserved communities” and inserting  
19 “public resources, and rehabilitative issues,  
20 including studies of the impact of such dis-  
21 eases in rural and underserved commu-  
22 nities, health economic studies to dem-  
23 onstrate the cost-effectiveness of providing  
24 independent living resources and support  
25 to patients with various forms of muscular

1 dystrophy, and studies to determine opti-  
2 mal clinical care interventions for adults  
3 with various forms of muscular dys-  
4 trophy”; and

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

7 “(F) The development of clinical interven-  
8 tions to improve the health of adults with var-  
9 ious forms of muscular dystrophy.”; and

10 (5) in subsection (g), by striking “for the var-  
11 ious forms of muscular dystrophy by prioritizing the  
12 achievement of the goals related to this topic in the  
13 plan under subsection (e)(1)” and inserting “and  
14 shall, not later than 6 months after the date of en-  
15 actment of the Paul D. Wellstone Muscular Dys-  
16 trophy Community Assistance, Research and Edu-  
17 cation Amendments of 2013, in coordination with  
18 appropriate Federal agencies, including relevant of-  
19 fices within the Food and Drug Administration and  
20 supported by the National Institutes of Health and  
21 Department of Defense, develop a plan to expedite  
22 the evaluation and approval of emerging therapies  
23 and personalized medicines that have the potential  
24 to decrease fatal disease progression across the var-  
25 ious forms of muscular dystrophy”.

1 **SEC. 3. SURVEILLANCE AND RESEARCH REGARDING MUS-**  
2 **CULAR DYSTROPHY.**

3 Section 317Q of the Public Health Service Act (42  
4 U.S.C. 247b–18) is amended—

5 (1) in the second sentence of subsection (b), by  
6 inserting before the period the following: “and en-  
7 sure that the program captures data from different  
8 racial and ethnic populations, and that such data  
9 are made publicly available to investigators con-  
10 ducting public or private research on muscular dys-  
11 trophy”; and

12 (2) in subsection (c), by adding at the end the  
13 following: “The Secretary shall also foster ongoing  
14 engagement and collaboration between the surveil-  
15 lance program and centers of excellence.”.

16 **SEC. 4. INFORMATION AND EDUCATION.**

17 Section 5(c) of the Muscular Dystrophy Community  
18 Assistance, Research and Education Amendments of 2001  
19 (42 U.S.C. 247b–19(c)) is amended by adding at the end  
20 the following:

21 “(4) Update and widely disseminate existing  
22 Duchenne-Becker muscular dystrophy care consider-  
23 ations for pediatric patients, develop and widely dis-  
24 seminate Duchenne-Becker muscular dystrophy care  
25 considerations for adult patients, and develop and  
26 widely disseminate acute care considerations for all

1 muscular dystrophy populations. The care consider-  
2 ations should build upon existing efforts currently  
3 underway for congenital muscular dystrophy,  
4 fascioscapulohumeral muscular dystrophy, limb-gir-  
5 dle muscular dystrophy, and myotonic muscular dys-  
6 trophy, and incorporate strategies specifically re-  
7 sponding to the findings of the national transitions  
8 survey of minority, young adult and adult commu-  
9 nities of muscular dystrophy patients.”.

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