

Public Law 113–166  
113th Congress

An Act

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

Sept. 26, 2014  
[H.R. 594]

*Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,*

**SECTION 1. SHORT TITLE.**

This Act may be cited as the “Paul D. Wellstone Muscular Dystrophy Community Assistance, Research and Education Amendments of 2014”.

**SEC. 2. INITIATIVE THROUGH THE DIRECTOR OF THE NATIONAL INSTITUTES OF HEALTH.**

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

(1) in subsection (a)(1)—

(A) by striking “Muscoskeletal” and inserting “Musculoskeletal”; and

(B) by inserting “Becker, congenital muscular dystrophy, limb-girdle muscular dystrophy,” after “Duchenne,”;

(2) in subsection (b)—

(A) in paragraph (2)—

(i) by striking “genetics,” at the second place it appears; and

(ii) by inserting “cardiac and pulmonary function, and” after “imaging,”; and

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

(3) in subsection (d)—

(A) in paragraph (2)—

(i) in the matter preceding subparagraph (A), by striking “15” and inserting “18”; and

(ii) in subparagraph (A)—

(I) by striking “and the Food and Drug Administration” and inserting “, the Food and Drug Administration, and the Administration for Community Living”;

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

(III) by striking “such as the Department of Education” and inserting “including the Department of Education and the Social Security Administration”; and

Paul D.  
Wellstone  
Muscular  
Dystrophy  
Community  
Assistance,  
Research and  
Education  
Amendments  
of 2014.  
42 USC 201 note.

(B) in paragraph (4)(B), by inserting “, but shall meet no fewer than two times per calendar year” before the period; and

(4) in subsection (e)—

(A) in paragraph (1)—

(i) in the matter preceding subparagraph (A), by striking “through the national research institutes” and inserting “through the agencies represented on the Coordinating Committee pursuant to subsection (d)(2)(A)”; and

(ii) in subparagraph (A)—

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

(II) by inserting “, studies to demonstrate the cost-effectiveness of providing independent living resources and support to patients with various forms of muscular dystrophy, and studies to determine optimal clinical care interventions for adults with various forms of muscular dystrophy” after “including studies of the impact of such diseases in rural and underserved communities”; and

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

### **SEC. 3. SURVEILLANCE AND RESEARCH REGARDING MUSCULAR DYSTROPHY.**

The second sentence of section 317Q(b) of the Public Health Service Act (42 U.S.C. 247b–18(b)) is amended by inserting before the period the following: “and, to the extent possible, ensure that data be representative of all affected populations and shared in a timely manner”.

### **SEC. 4. INFORMATION AND EDUCATION.**

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

(1) in paragraph (2)—

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

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

(C) by striking “and” at the end;

(2) by redesignating paragraph (3) as paragraph (4);

(3) by inserting after paragraph (2) the following:

“(3) in developing and updating care considerations under paragraph (2), incorporate strategies specifically responding to the findings of the national transitions survey of minority, young adult, and adult communities of muscular dystrophy patients; and”; and

(4) in paragraph (4), as redesignated, by inserting “various” before “other forms of muscular dystrophy”.

Approved September 26, 2014.

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LEGISLATIVE HISTORY—H.R. 594 (S. 315):

HOUSE REPORTS: No. 113–556 (Comm. on Energy and Commerce).

CONGRESSIONAL RECORD, Vol. 160 (2014):

July 28, considered and passed House.

Sept. 18, considered and passed Senate.

