

**Paul D. Wellstone Muscular Dystrophy Community
Assistance, Research and Education Amendments of 2014**

[Public Law 113–166]

[This law has not been amended]

[Currency: This publication is a compilation of the text of Public Law 113-166. It was last amended by the public law listed in the As Amended Through note above and below at the bottom of each page of the pdf version and reflects current law through the date of the enactment of the public law listed at <https://www.govinfo.gov/app/collection/comps/>**]**

[Note: While this publication does not represent an official version of any Federal statute, substantial efforts have been made to ensure the accuracy of its contents. The official version of Federal law is found in the United States Statutes at Large and in the United States Code. The legal effect to be given to the Statutes at Large and the United States Code is established by statute (1 U.S.C. 112, 204).**]**

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

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

SECTION 1. [42 U.S.C. 201 note] 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

(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)”;

(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”.