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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

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A BILL

To reauthorize and extend the Paul D. Wellstone Muscular Dystrophy Community Assistance, Research, and Education Amendments of 2008.

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 2013''.

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, myotonic, facioscapulohumeral muscular dystrophy (referred to in this section as 'FSHD'), Congenital muscular dystrophy, Limb-girdle muscular dystrophy,'' after ''Duchenne,'';

(2) in subsection (b)—

(A) in paragraph (2), by inserting ''cardiac and pulmonary function,'' after ''imaging, genetics,''; 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), by striking ''children with muscular dystrophy, such as the Department of Education'' and inserting ''children and adults with muscular dystrophy, such as the Department of

Education, the Social Security Administration, the United States Administration for Community Living''; and

(B) in paragraph (4)(B), by inserting '', and shall meet no less than two times per calendar year'' before the period;

(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), by striking ''and rehabilitative issues, including studies of the impact of such diseases in rural and underserved communities'' and inserting ''public resources, and rehabilitative issues, including studies of the impact of such diseases in rural and underserved communities, health economic 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''; and

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

''(F) The development of clinical interventions to improve the health of adults with various forms of muscular dystrophy.''; and

(5) in subsection (g), by striking ''for the various forms of muscular dystrophy by prioritizing the achievement of the goals related to this topic in the plan under subsection (e)(1)'' and inserting ''and shall, not later than 6 months after the date of enactment of the Paul D. Wellstone Muscular Dystrophy Community Assistance, Research and Education Amendments of 2013, in coordination with appropriate Federal agencies, including relevant offices within the Food and Drug Administration and supported by the National Institutes of Health and Department of Defense, develop a plan to expedite the evaluation and approval of emerging therapies and personalized medicines that have the potential to decrease fatal disease progression across the various forms of muscular dystrophy''.

SEC. 3. SURVEILLANCE AND RESEARCH REGARDING MUSCULAR DYSTROPHY.

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

(1) in the second sentence of subsection (b), by inserting before the period the following: ''and ensure that the program captures data from different racial and ethnic populations, and that such data are made publicly available to investigators conducting public or private research on muscular dystrophy''; and

(2) in subsection (c), by adding at the end the following: ''The Secretary shall also foster ongoing engagement and collaboration between the surveillance program and centers of excellence.''.

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 by adding at the end the following:

''(4) Update and widely disseminate existing Duchenne-Becker muscular dystrophy care considerations for pediatric patients, develop and widely disseminate Duchenne-Becker muscular dystrophy care considerations for adult patients, and develop and widely disseminate acute care considerations for all

muscular dystrophy populations. The care considerations should build upon existing efforts currently underway for congenital muscular dystrophy, fascioscapulohumeral muscular dystrophy, limb-girdle muscular dystrophy, and myotonic muscular dystrophy, and incorporate strategies specifically responding to the findings of the national transitions survey of minority, young adult and adult communities of muscular dystrophy patients.''.

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