

June 12, 2014

The Honorable Fred Upton
Chairman
Committee on Energy and Commerce
United States House of Representatives
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Henry A. Waxman
Ranking Member
Committee on Energy and Commerce
United States House of Representatives
2322A Rayburn House Office Building
Washington, DC 20515

The Honorable Joe Pitts
Chairman
Energy and Commerce Health Subcommittee
U.S. House of Representatives
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Frank Pallone, Jr.
Ranking Member
Energy and Commerce Health Subcommittee
U.S. House of Representatives
2322A Rayburn House Office Building
Washington, DC 20515

Dear Chairman Upton, Ranking Member Waxman, Chairman Pitts, and Ranking Member Pallone:

On behalf of the Muscular Dystrophy Association, a voluntary health organization which funds services, treatments, and research for cures for the estimated 150,000 people living in the United States with one of the nine forms of muscular dystrophy, we urge you to mark-up and approve H.R. 594, legislation to update the Muscular Dystrophy Community Assistance, Research, and Education Amendments (MD-CARE Act).

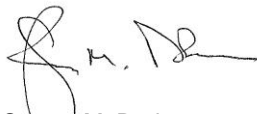
The MD-CARE Act, originally enacted by Congress in 2001 and updated in 2008, has yielded great advances in understanding the specific causes of the various forms of muscular dystrophies, the mechanisms of these diseases, identification of therapeutic targets, and now even clinical trial development. The Paul D. Wellstone Centers of Muscular Dystrophy Excellence are a model of how best to incentivize therapy development and ensure that research is not conducted in silos. In 2001, not 1 clinical drug trial had been conducted for muscular dystrophy. Today there are more than 67 clinical trials of drugs or therapies for muscular dystrophy, and currently more than 40 clinical trials are under way.

The MD-CARE Act has also served to standardize and optimize clinical care throughout the United States by developing care standards for each form of muscular dystrophy and then disseminating them to clinicians and patients throughout the United States. The inter-agency Muscular Dystrophy Coordinating Committee developed the MD Action Plan in 2005 and has worked to eliminate duplication and maximize opportunities for collaboration with government and private partners.

Thanks to the MD-CARE Act, we have made a significant impact on the quality of life and life expectancy of children and adults diagnosed with muscular dystrophy. However, the muscular dystrophies continue to be among the nation's most devastating health conditions, and most forms of muscular dystrophy are still considered to be 100% fatal.

Accordingly, we urge your approval of H.R. 594, which will build upon its successes of the MD-CARE Act as well as ensure that the law keeps continues to keep pace with the advances and investment that have been made to date. Muscular dystrophy affects Americans of all ages, ethnicities, and economic strata. Today – on behalf of each of these babies, children, teens, adults, and their families – thank you for your important work on this legislation.

Sincerely,



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