Muscular Dystrophy Association
mda.org

May 19, 2015

The Honorable Fred Upton
Chairman, Committee on Energy & Commerce
U.S. House of Representatives
Washington, DC 20515

The Honorable Joe Pitts
Chairman
Committee on Energy & Commerce
Subcommittee on Health
U.S. House of Representatives
Washington, DC 20515

The Honorable Diana DeGette
Committee on Energy & Commerce
U.S. House of Representatives
Washington, DC 20515

The Honorable Frank Pallone
Ranking Member
Committee on Energy & Commerce
U.S. House of Representatives
Washington, DC 20515

The Honorable Gene Green
Ranking Member
Committee on Energy & Commerce
Subcommittee on Health
U.S. House of Representatives
Washington, DC 20515

Dear Chairmen Upton and Pitts and Ranking Members Pallone, Green, and DeGette:

On behalf of the thousands of families and individuals we serve, the Muscular Dystrophy Association (MDA) appreciates your leadership and commitment to 21st Century Cures Act. We see many opportunities and face great challenges—we commend the Energy & Commerce Committee for setting forth a collaborative structure in the 21st Century Cures Act in which government, individuals and industry work together to accelerate the discovery, development and delivery of cures to patients.

MDA is the leading nonprofit health agency dedicated to saving and improving the lives of people affected by neuromuscular diseases including the muscular dystrophies, spinal muscular atrophy (SMA), amyotrophic lateral sclerosis (ALS), Friedreich's ataxia (FA) and others. Despite more than six decades of investments, collaborations and research progress, people living with neuromuscular diseases still are in urgent need of comprehensive treatments and cures. Infants diagnosed with spinal muscular atrophy

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type I (SMA I) typically die before age two. Adults diagnosed with amyotrophic lateral sclerosis (ALS) typically die three to five years from the time of symptom onset. Those with Duchenne muscular dystrophy (DMD) have seen an improvement in their lifespan, as it is becoming more common to see individuals with DMD living into their 30s—but that lifespan is far too short.

We have seen first hand how public-private partnerships can spur dramatic advancements in understanding the mechanisms of and potential treatments for neuromuscular disease. To that end, MDA has awarded over $1 billion in research grants to propel the development of potential therapies since its inception. But the need for additional research can only be met with increased federal funding.

MDA applauds the Committee for increasing National Institutes of Health (NIH) funding set forth in the 21st Century Cures Act, which combined with the proposed NIH Innovation Fund, will help fuel the research that is necessary to save and improve the lives of those living with neuromuscular diseases. MDA appreciates the Committee's creativity and extraordinary efforts in pursuing this legislation.

Sincerely,

Steven Derks
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