

June 12, 2014

The Honorable Michael Burgess
Vice Chairman
Subcommittee on Health
Committee on Energy and Commerce
2336 Rayburn House Office Building
Washington, DC 20515

The Honorable Eliot Engel
Subcommittee on Health
Committee on Energy and Commerce
2161 Rayburn HOB
Washington, DC 20515

Dear Vice Chairman Burgess and Representative Engel:

Parent Project Muscular Dystrophy, the leading advocacy organization striving to end Duchenne Muscular Dystrophy and to improve the quality of life for those with the disease and their families, urges you to advance H.R. 594 to help ensure continued progress against all forms of muscular dystrophy. First enacted in 2001 and updated in 2008, the Muscular Dystrophy Community Assistance, Research & Education Act – or MD CARE Act – is a shining success story. Since its enactment this law has leveraged limited federal resources to catalyze efforts that have:

- ✓ Increased by about 10 years over the same period of time the average lifespan of patients with the most common form of the disease;
- ✓ Dramatically improved and standardized clinical care helping drive improved health outcomes; and
- ✓ Transformed a barren potential therapeutics landscape into one that today counts 32 potential therapies in various stages of clinical investigation.

Had Congress not taken the bold step of enacting the initial MD CARE Act in 2001 and 2008 update, much of this progress likely would not have occurred. The MD CARE Act epitomizes what is possible when Congress commits itself to advancing sound, evidence-based biomedical research and public health policy.

While much progress has occurred, more work remains. To maximize the federal commitment made over the years and to achieve the end goal of safe and effective treatments and therapies for all forms of muscular dystrophy, **we urge you to support the MD CARE Amendments Act of 2013.**

This legislation recognizes the challenging fiscal climate by providing no new authorization of appropriations and proposes a small set of targeted improvements intended to ensure the law remains as effective as possible by focusing on the most critical areas. For example, the amendments would:

- ✓ Enhance existing research efforts to include a focus on cardiac, pulmonary, and other issues of importance to adults with muscular dystrophy;
- ✓ Update existing care standards and filling gaps that remain, particularly in properly caring for adults with Duchenne and other forms of muscular dystrophy;
- ✓ Intensify surveillance and tracking of all the muscular dystrophies including capturing more diverse populations; and
- ✓ Support adults with Duchenne so they can live independent, productive and rewarding lives.

The Muscular Dystrophy CARE Amendments Act of 2013 will enable us to continue achieving the research and clinical care breakthroughs that have transformed lives for all Americans impacted by these conditions. We urge you to join us in recognizing the success of this work by supporting the MD CARE Amendments Act today.

Sincerely,

A handwritten signature in black ink, appearing to read "Pat Furlong". The signature is fluid and cursive, with a large initial "P" and a long, sweeping tail.

Pat Furlong
President/CEO
Parent Project Muscular Dystrophy