

February 8, 2013

The Honorable Amy Klobuchar  
302 Hart Senate Office Building  
Washington, D.C. 20510

The Honorable Michael C. Burgess, MD  
2336 Rayburn House Office Building  
Washington, D.C. 20515

The Honorable Roger Wicker  
555 Dirksen Senate Office Building  
Washington, D.C. 20510

The Honorable Eliot Engel  
2161 Rayburn House Office Building  
Washington, D.C. 20515

Dear Senator Klobuchar, Senator Wicker, Congressman Burgess, and Congressman Engel,

We, the undersigned organizations, applaud you for introducing legislation to update the Muscular Dystrophy Community Assistance, Research and Education Amendments (MD-CARE Act), to build upon the tremendous success achieved in coordinating and focusing federal research on all nine forms of muscular dystrophy, developing epidemiologic data, and developing and disseminating patient care guidelines -- all of which have made a significant impact on the quality of life and life expectancy of children and adults diagnosed with muscular dystrophy.

Congress enacted the original MD-CARE Act in 2001 and reauthorized the law in 2008. In particular, NIH's research through the Senator Paul Wellstone Muscular Dystrophy Cooperative Research Centers, have been responsible for catalyzing many of the scientific breakthroughs across the muscular dystrophies, have led to the expansion and intensification of MD research, including the leveraging of significant non-federal sources of funding. Since 2001, there have been 67 clinical trials of drugs or therapies for muscular dystrophy and there are currently 37 clinical trials underway. A number of the potential therapies now in clinical investigation can be traced to the basic research efforts sponsored by the Centers.

These amendments would build upon the success of this law and update the MD-CARE Act to:

- Expand the eligible fields of research by the Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers to include cardiac and pulmonary function, and requires that the program support robust research momentum through the centers of excellence.
- Require that the MDCC meet no less than 2 times per year and also requires the Coordinating Committee to update the plan for conducting and supporting research and education on muscular dystrophy, including a new emphasis on studying and developing optimal clinical care interventions and justifying independent living resources support for adults with various forms of muscular dystrophy.

- Direct the CDC to update and widely disseminate existing Duchenne-Becker muscular dystrophy care considerations for pediatric patients as well as develop and widely disseminate care considerations for adults with the disease.
- Direct the CDC to develop and disseminate acute care considerations for all muscular dystrophy populations.

We thank you for your leadership on this issue, and we look forward to working with you to support this important legislation in the 113<sup>th</sup> Congress.

Sincerely,

Charley's Fund  
Coalition Duchenne  
Cure CMD  
CureDuchenne  
Defeat Duchenne, Inc.  
Duchenne San Diego  
Facioscapulohumeral Muscular Dystrophy Society (FSH Society)  
Foundation to Eradicate Duchenne (FED)  
Friends of FSH Research  
Hope for Javier  
Jain Foundation  
JB's Keys to DMD  
John Owen's Adventure, Inc  
Liam Hiatt Foundation  
Muscular Dystrophy Association (MDA)  
Parent Project Muscular Dystrophy (PPMD)  
Rally for Ryan, Inc.  
Save Our Boy Foundation  
Team Joseph  
Two Smiles One Hope Foundation  
Zack Heger Foundation