

Congress of the United States

Washington, DC 20515

Cosponsor H.R. 5265, the Paul D. Wellstone Muscular Dystrophy Community Assistance, Research and Education Amendments of 2008

*Endorsed by the Parent Project Muscular Dystrophy (PPMD)
& the Muscular Dystrophy Association (MDA)*

Dear Colleague:

Muscular Dystrophy is a genetic disease which results in progressive degeneration of skeletal muscles and other organs, notably the heart. There are nine muscular dystrophies affecting over 300,000 individuals in the United States. The most lethal is Duchenne Muscular Dystrophy, which affects 1 in every 3,500 boys. There is no cure.

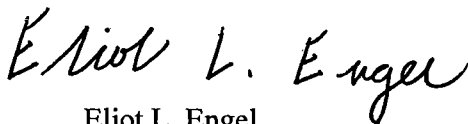
Prior to 2001, there were few resources directed toward research and development of therapies and care models for those afflicted with muscular dystrophy. To address this issue, the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 was introduced. Congress overwhelmingly supported the legislation. There were 310 cosponsors on the original legislation and the bill passed the House of Representatives without opposition. The MD-CARE Act was signed into law (P.L. 107-84) in December of 2001.

The law specified a number of provisions for expanding and intensifying research on muscular dystrophy. These efforts included the establishment of six scientific centers of excellence, the creation of a Muscular Dystrophy Coordinating Committee (MDCC) to develop plans for supporting research and education on muscular dystrophy, and an expansion by the Centers for Disease Control and Prevention (CDC) into epidemiological activities regarding muscular dystrophy.

The MD-CARE Act authorization expired in 2006 and the MD community is seeking to continue to build on the great strides that have been made as a result of the original bill. The reauthorization of the Paul D. Wellstone MD-CARE Amendments officially names the Centers of Excellence the Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers. In addition, it ensures that data collection at CDC is updated regularly with a requirement for regular reports to Congress. The bill also requires the Agency for Healthcare Research and Quality to work with appropriate medical or patient organizations to finalize an initial set of care considerations and for CDC to disseminate that information to targeted audiences.

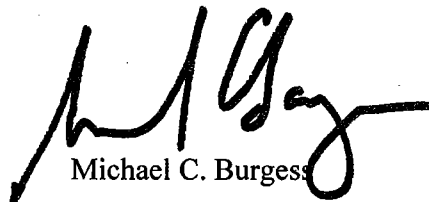
We hope you will consider cosponsoring the Paul D. Wellstone Muscular Dystrophy Community Assistance, Research and Education Amendments of 2008 and help continue the momentum that was created from the original legislation. This bill will provide hope to countless families coping with muscular dystrophy. Please contact Emily Gibbons with Rep. Engel at 5-2464 or Josh Martin with Rep. Burgess at 5-7772 for more information or to sign on as cosponsor.

Sincerely,



Eliot L. Engel

Member of Congress



Michael C. Burgess

Member of Congress