



The Honorable Michael C. Burgess, M.D.
U.S. House of Representatives
2336 Rayburn House Office Building
Washington, DC 20515

The Honorable Eliot L. Engel
U.S. House of Representatives
2161 Rayburn House Office Building
Washington, DC 20515

Dear Representatives Burgess and Engel:

On behalf of the thousands of Americans with Congenital Muscular Dystrophy (CMD), we strongly support The Paul D. Wellstone Muscular Dystrophy Community Assistance, Research and Education (MD CARE) Amendments Act of 2013 (H.R. 594).

Cure CMD is a nonprofit organization dedicated to finding treatments and, eventually, a cure for the devastating ravages of the congenital muscular dystrophies. CMD is a group of diseases causing muscle weakness at birth or within the first two years of childhood. Several defined genetic mutations cause muscles to break down faster than they can repair or grow. A child with CMD may have various neurological or physical impairments and may never gain the ability to walk. Cure CMD represents the network of family, friends, caretakers and affected individuals tirelessly battling this devastating disease every day.

CMD is a progressive disease without treatment. The future is bleak. It is a life that ends after years of non-stop caregiving, dependency, hospitalizations and loss...loss of ambulation, loss of integration within society, loss of ability to sign and communicate, loss of an ability to breathe on one's own and loss of life.

Cure CMD is deeply appreciative of the critical support the MD CARE Act has provided to muscular dystrophy research and the steadfast pathway toward clinical trials. The pulmonary and cardiac research supported is making significant advances in better understanding and treating all muscular dystrophies including CMD. Without this vital research, the CMD community will be setback years in making progress and improving the quality of life of those suffering with this devastating disorder. It is critical to our communities that the strong momentum of scientific progress is able to be maintained.

Sincerely,

Patrick May, Chairman, Cure CMD
pat.may@curecmd.org