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[Your name]

 [Address]

[City, State, ZIP]

The Honorable [Name]

[Address]

[City, State, ZIP]

[Date]

Dear [Representative or Senator] [Last Name],

My name is [your name], and I am writing to you on behalf of the myotonic dystrophy community. I want to introduce you to myotonic dystrophy (DM), a disease that you may not know much about. DM is the most common form of adult-onset muscular dystrophy and is the only form that has impacts on cognition and brain function, in addition to impacts on the heart, lungs, muscles, gastrointestinal system, and many other parts of the body. Because DM affects many different parts of the body, symptoms can vary widely and it is significantly under-diagnosed. The congenital and juvenile-onset forms of this disease are particularly devastating. As a genetic disease, it impacts entire families and becomes more severe with each successive generation. There are currently no treatments or a cure for DM.

I understand firsthand the need to invest in DM research. [Insert personal connection to DM, 1-2 sentences.]

DM is considered a breakthrough disease in terms of its ability to advance science around triplet repeat, toxic-RNA and other neuromuscular disorders, and presents an enormous research opportunity that extends far beyond this disease alone. Researchers are very close to finding the answers to unlock and restore cell function in the body systems that are attacked by this disease. Scientists have developed a treatment that reversed the condition in laboratory mice in 2006, and the first human clinical trials for this treatment began in late 2014.

Few people ever have the opportunity in their lifetime to help cure or reverse a form of muscular dystrophy, but you are in a unique position to help advance the research and claim victory over what we hope to soon refer to as an “untreatable progressive disease of the past.” As you know, there are several issues important to the rare disease community facing Congress in 2015, including the 21st Century Cures Initiative (H.R. 6) and restoration of NIH and other federal funding for research. I hope you will engage in the fight to find treatments for diseases like DM through supporting 21st Century Cures, and restoring 2009 NIH funding levels. We need your support!

Thank you for taking the time to learn about the impact that DM has had on my family's life. I look forward to speaking with you in the future about these issues.

Sincerely,

[Your name]