**MDF Advocacy Week 2022**

**Draft Letter Requesting Support for MDF Advocacy Priorities**

Below is a draft letter you can use to request support for MDF advocacy priorities. Please personalize your email by adding your personal story of living with myotonic dystrophy or caring for a friend or family member living with myotonic dystrophy and update or remove all bolded sections.

**Questions?** Please contact Kevin Brennan, MDF’s advocacy consultant, if you have any questions and to let us know if you were able to schedule virtual meetings and email notes of support for our research advocacy objectives. Kevin can be reached at [kbrennan@bluebird-strategies.com](mailto:kbrennan@bluebird-strategies.com).

*Dear* ***Representative or Senator:***

*As a volunteer advocate with the Myotonic Dystrophy Foundation, I am writing to ask for your support for increased federal funding for myotonic dystrophy research. I am a constituent who lives in* ***EVERYTOWN, STATE*** *and I have or have a loved one with myotonic dystrophy.*

***[ADD PERSONAL STORY]***

*Myotonic dystrophy is a multi-systemic inherited genetic disease that affects at least 1 in 2,300 people or over 150,000 individuals in the United States. The disease is caused by a mutation in a gene required for normal muscle function which prevents the gene from carrying out its function properly. Individuals affected by myotonic dystrophy may have skeletal muscle problems, heart function abnormalities, breathing difficulties, cataracts, issues with speech and swallowing (dysarthria and dysphagia), cognitive impairment, excessive daytime sleepiness, or diabetic symptoms. It causes disability and can reduce life expectancy. There are currently no Food and Drug Administration (FDA) approved treatments for myotonic dystrophy, and federal funding for myotonic dystrophy has lagged other similar genetic disorders.*

*Specifically, we are asking you to express your support for our request for the inclusion of a Peer-Reviewed Myotonic Dystrophy initiative totally $10 million as part of the fiscal year 2023 Defense Appropriation’s bill’s Congressionally Directed Peer Reviewed Medical Research Program (CDMRP). Additionally, we are asking the Appropriations Committee to support the establishment of a new initiative at the National Institutes of Health to further study the rapidly emerging science on DNA repeat expansions, which causes over 50 distinct diseases including myotonic dystrophy. This new trans-NIH Repeat Expansion Disease Initiative (REDI) within the Office of the Director will increase federal funding for research on repeat expansions to support scientific discoveries that will lead to treatments and cures for myotonic dystrophy and related genetic disorders and conditions.*

*I appreciate your kind attention to this request and look forward to your reply.*

*Sincerely,*

***MDF ADVOCATE NAME***

***STREET ADDRESS***

***HOMETOWN, STATE***

***EMAIL ADDRESS***