**RARE DISEASE DAY: SAMPLE CONGRESSIONAL LETTER**

February 28, 2021

*Visit* [*www.congress.gov*](http://www.congress.gov) *to look up addresses: Sample Below*

The Honorable Jane Smith

1234 House or Senate Office Building

Washington, D.C. 20515 or 20510

Dear Representative or Senator Smith:

As a volunteer advocate with the Myotonic Dystrophy Foundation, I am writing to you on Rare Disease Day 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.

Myotonic dystrophy is a multi-systemic inherited genetic disease that affects at least 1 in 2,100 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 behind other similar genetic disorders.

I urge you to support the Myotonic Dystrophy Foundation’s Rare Disease Day advocacy priorities. **We ask Congress to increase myotonic dystrophy research funding as part of the fiscal year 2022 National Institutes of Health budget. Additionally, we ask the Senate to continue to include myotonic dystrophy as an eligible condition for research funding under the Department of Defense Peer Reviewed Medical Research Program (PRMRP) in the fiscal year 2022 Senate Defense Appropriations bill.** Finally, we are anticipating Congress will consider legislation recognizing Myotonic Dystrophy Awareness Day this year, and we hope we can count on your support. We believe that increased awareness and funding for myotonic dystrophy research that will improve health outcomes, reduce disability, and increase life expectancy for individuals living with the disease.

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

Sincerely,

MDF ADVOCATE NAME

STREET ADDRESS

HOMETOWN, STATE

EMAIL ADDRESS