April 17, 2023

The Honorable [YOUR SENATORS NAME]

Senate Office Building

Washington, D.C. 20510

Dear Senator:

As a Myotonic Dystrophy Foundation advocate from [ YOUR HOME STATE ], I am writing to ask for your support to maintain eligibility for myotonic dystrophy research awards for the 7th year in a row as part of the fiscal year 2024 Department of Defense (DoD) Peer-Reviewed Medical Research Program (PRMRP). To date PRMRP has funded $16 million in new myotonic dystrophy research which has helped advance our understanding of this rare genetic disorder. [*I was diagnosed with myotonic dystrophy, care for a family member living with myotonic dystrophy, or am a friend of a person living with myotonic dystrophy]* and I would appreciate your support.

Myotonic dystrophy is a multi-systemic inherited genetic disease that affects as many as 1 in 2,100 people or over 150,000 individuals in the United States. It impacts adults and children as well as veterans and active-duty military personnel. While there is limited prevalence data on this rare genetic disorder, the Myotonic Dystrophy Foundation has worked with many veterans who were undiagnosed during their service and unfairly discharged because the disease prevented them from carrying out simple tasks like putting on protective gear like a gas mask or attaching dangerous munitions to aircraft. We believe new research funding will help us better understand and diagnose myotonic dystrophy and discover new treatments and a cure which will benefit civilians, active-duty military personnel, and veterans.

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. Americans entering military service with undiagnosed myotonic dystrophy oftentimes have mild symptoms which grow more serious as they grow older. These cognitive impairments, daytime sleepiness and muscle problems are often viewed as a lack of military disciple rather than symptoms of a serious disease. It leads to discharge and a loss of veterans’ benefits. Only afterwards, are these veterans diagnosed and begin treatment.

Myotonic dystrophy also 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. I would deeply appreciate your support of our request and look forward to your reply.

Sincerely,

[YOUR NAME

YOUR STREET ADDRESS,

YOUR CITY, YOUR STATE, YOUR ZIP]