Congress of the United States
Washington, DC 20515

April 8, 2024

The Honorable Kay Granger
Chair
Committee on Appropriations
H-307, The Capitol
Washington, D.C. 20515

The Honorable Rosa DeLauro
Ranking Member
Committee on Appropriations
1036 Longworth House Office Building
Washington, D.C. 20515

The Honorable Ken Calvert
Chair
Committee on Appropriations
Subcommittee on Defense
H-307, The Capitol
Washington, D.C. 20515

The Honorable Betty McCollum
Ranking Member
Committee on Appropriations
Subcommittee on Defense
1036 Longworth House Office Building
Washington, D.C. 20515

Dear Chair Granger, Ranking Member DeLauro, Chair Calvert, and Ranking Member McCollum:

As you lead efforts to draft the Fiscal Year (FY) 2025 Department of Defense Appropriations bill, we ask that you include $10 million for peer-reviewed myotonic dystrophy research funding as part of the Congressionally Directed Medical Research Program (CDMRP). As you know, the Senate Appropriations Committee has made myotonic dystrophy an eligible research focus for seven consecutive years as part of the Department of Defense (DoD) Peer-Reviewed Medical Research Program (PRMRP). The committee's support for this research has funded almost $17 million in innovative peer-reviewed research for this rare genetic disorder for which there are still no FDA-approved treatments. We thank you for your continued commitment to funding myotonic research and are confident this investment will help accelerate the first FDA-approved treatment and cure.

Myotonic dystrophy is a form of muscular dystrophy and a multi-systemic inherited genetic disease that affects as many as 1 in 2,100 people or over 150,000 individuals in the U.S. Individuals affected by this disease 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 impacts adults and children as well as veterans, active-duty military personnel, and their families. 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 discipline rather than symptoms of a serious disease. Veterans who are undiagnosed during their service are unfairly discharged because the disease prevents them from carrying out simple tasks like putting on protective gear like a gas mask or attaching dangerous munitions to aircraft.

Given the complexities and variability of the disease, myotonic dystrophy is often undiagnosed or misdiagnosed – on average, taking families more than a year to discover their diagnosis. It remains one of the least funded rare genetic disorders, and new research funding will help us better understand and diagnose myotonic dystrophy and eventually find a cure.

We understand the challenges you face in setting FY 2025 appropriation levels and priorities within this critically important spending bill and appreciate your consideration of this request.

Sincerely,

Jen A. Riggans
Member of Congress

Jared Moskowitz
Member of Congress

Brian Fitzpatrick
Member of Congress

Paul Tonko
Member of Congress

Angie Craig
Member of Congress

Jimmy Panetta
Member of Congress

Earl Blumenauer
Member of Congress

Debbie Dingell
Member of Congress

Dean Phillips
Member of Congress

James P. McGovern
Member of Congress

Thomas R. Suozzi
Member of Congress