United States Senate

WASHINGTON, DC 20510

May 12, 2026

The Honorable Susan Collins
Chair
Committee on Appropriations
S-128, The Capitol
Washington, D.C. 20510

The Honorable Patty Murray
Vice Chair
Committee on Appropriations
S-128, The Capitol
Washington, D.C. 20510

The Honorable Mitch McConnell
Chair
Committee on Appropriations
Subcommittee on Defense
S-128, The Capitol
Washington, D.C. 20510

The Honorable Chris Coons
Ranking Member
Committee on Appropriations
Subcommittee on Defense
S-128, The Capitol
Washington, D.C. 20510

Dear Chair Collins, Vice Chair Murray, Chair McConnell, and Ranking Member Coons:

As you draft the Fiscal Year (FY) 2027 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 Programs (CDMRP). Myotonic dystrophy has been an eligible research focus for nine consecutive years as part of the Department of Defense Peer-Reviewed Medical Research Program (PRMRP) and researchers have been awarded $23 million over the last decade, but there are still no approved treatments and no cure. Myotonic dystrophy researchers are advancing our understanding of the causes of progressive muscle weakness, cardiac conduction abnormalities, and respiratory impairments that will lead to treatments that will benefit warfighter readiness and improve the lives of individuals with neuromuscular diseases like myotonic dystrophy.

Myotonic dystrophy type 1 is the most common form of muscular dystrophy reported among activity-duty military servicemembers according to data collected through the Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STARnet), a Centers for Disease Control and Prevention-funded multi-state consortium. Myotonic dystrophy is a multi-systemic inherited, progressive, genetic disease that affects muscle function in as many as 1 in 2,100 people, including over 150,000 people in the U.S. and over 3 million people worldwide. Considered to be one of the most variable diseases in medicine, it impacts people of all ages, ethnicities, and backgrounds including children, adults, active-duty military personnel, and veterans.

Symptoms of this disease include 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 often have mild symptoms that worsen and become debilitating with time. Common symptoms including cognitive impairments,

excessive daytime sleepiness and muscle problems have been incorrectly viewed as a lack of military discipline rather than symptoms of a serious disease.

Myotonic dystrophy remains one of the least-funded genetic disorders. New, modest investments in myotonic dystrophy research will improve the lives of thousands of Americans by advancing basic science and accelerating the day this disease has its first Food and Drug Administration-approved treatment and a cure. We appreciate the Committee's consideration of this request.

Sincerely,

Amy Klobuchar
United States Senator

Mike Rounds
United States Senator

Kevin Cramer
United States Senator

Raphael Warnock
United States Senator

Chris Van Hollen
United States Senator

Tim Kaine
United States Senator

Kirsten Gillibrand
United States Senator

Jeffrey A. Merkley
United States Senator

Michael F. Bennet
United States Senator

Elissa Slotkin
United States Senator

Edward J. Markey
United States Senator

Angela D. Alsobrooks
United States Senator