United States Senate

WASHINGTON, DC 20510

June 2, 2025

The Honorable Mitch McConnell Chair. Subcommittee on Defense Committee on Appropriations United States Senate Washington, D.C. 20510

The Honorable Christopher Coons Ranking Member, Subcommittee on Defense Committee on Appropriations **United States Senate** Washington, D.C. 20510

Dear Chair McConnell and Ranking Member Coons:

As you draft the Fiscal Year (FY) 2026 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). As you know, the Senate Appropriations Committee has made myotonic dystrophy an eligible research focus for eight 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 \$21 million in innovative peer-reviewed research between FY 2018 through FY 2024 to pursue cutting-edge science that is advancing the field and will help us realize our goal of the first FDA-approved treatments and a cure-are confident this and future investments will accelerate the first FDA-approved treatment and cure for myotonic dystrophy.

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 people in the U.S. and over 3 million people worldwide. It impacts adults and children as well as veterans, active-duty military personnel, and their families, and is the result of a mutation in a gene required for normal muscle function. 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.

Americans entering military service with undiagnosed myotonic dystrophy oftentimes have mild symptoms, which grow more serious as they grow older. Additional research funding will advance our scientific understanding and help discover treatments and a cure which will benefit civilians, active-duty military personnel, and veterans.

Myotonic dystrophy is persistently one of the least-funded genetic disorders. New, modest investments in myotonic dystrophy research will improve the lives of thousands of Americans living by advancing basic science and accelerating the day we have our first FDA approved treatment and a cure. We understand the challenges the Committee faces in setting priorities within this critically important spending bill and appreciate its consideration of this request.

Sincerely,

United States Senator

United States Senator

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Tim Kaine
United States Senator

Angela D. alsobrooks

Angela Alsobrooks
United States Senator

Kirsten Gillibrand United States Senator

Chris Van Hollen United States Senator