

United States Senate

WASHINGTON, DC 20510

April 12, 2019

The Honorable Richard Shelby
Chairman
Defense Appropriations Subcommittee
122 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Dick Durbin
Ranking Member
Defense Appropriations Subcommittee
115 Dirksen Senate Office Building
Washington, DC 20510

Dear Chairman Shelby and Ranking Member Durbin:

As Senators committed to improving the health of children and adults living with intellectual disabilities in the United States, we respectfully request your continued commitment to sustaining federal investments in biomedical research focused on the treatment and cure of Fragile X and its related conditions.

Mutations of the Fragile X gene result in behavioral, developmental, cognitive, reproductive, and potentially life-ending neurodegenerative conditions across generations in families and impact affected individuals from cradle to grave. Fragile X syndrome and associated disorders result from a single-gene mutation, which is the most common, known inherited cause of intellectual disabilities and autism. In fact, research has shown that the Fragile X protein regulates nearly one half of the genes suspected of causing autism. Over 100,000 Americans have Fragile X syndrome, and over 1,500,000 Americans have a variation of the Fragile X mutation and as a result either have, or are at risk for developing, one of the conditions associated with Fragile X and passing the gene mutation to their children. The known premutation issues are Fragile X-associated tremor/ataxia syndrome, a condition similar to Parkinson's, and Fragile X-associated primary ovarian insufficiency, which causes infertility and early menopause.

The Committee's previous decade long support of Fragile X as one of the research areas authorized for the DOD's Peer Reviewed Medical Research Program funded some important research and has the potential to ease the burden of Fragile X and other intellectual and developmental disabilities on our military families. Military families are affected substantially by the financial and emotional costs of raising a child with intellectual and developmental disabilities, including Fragile X syndrome. This impact extends to the performance and readiness of service members and their units. Strides are being made towards effective treatments for Fragile X syndrome and other associated disorders while moving towards a cure. These treatments will help ease the burden on military families.

We are requesting that Fragile X be included as an authorized research area for the DOD's Peer Reviewed Medical Research Program for Fiscal Year 2020. While we understand the challenges the Committee faces in prioritizing requests, Fragile X has a significant impact on military families across generations in every state and district. The potential for effective treatments is within reach. We believe continued support for Fragile X research is imperative. The DOD's

research has been a significant contributor over the past decade, and we hope it will continue to be in the future.

We look forward to working with the Subcommittee on this important issue. Thank you for your consideration.

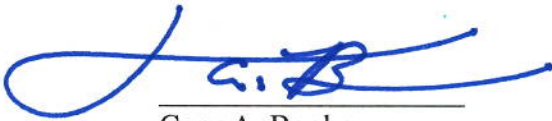
Sincerely,



Debbie Stabenow
United States Senator



Richard Blumenthal
United States Senator



Cory A. Booker
United States Senator



Sherrod Brown
United States Senator



Kirsten Gillibrand
United States Senator



Edward J. Markey
United States Senator



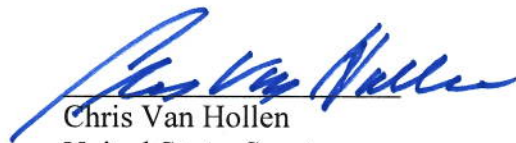
Gary C. Peters
United States Senator



Jack Reed
United States Senator



Kyrsten Sinema
United States Senator



Chris Van Hollen
United States Senator



Elizabeth Warren
United States Senator