

# United States Senate

WASHINGTON, DC 20510

March 26, 2015

Senator Thad Cochran  
Chairman  
Subcommittee on Defense  
Committee on Appropriations  
122 Senate Dirksen Building  
Washington, DC 20510

Senator Richard Durbin  
Ranking Member  
Subcommittee on Defense  
Committee on Appropriations  
115 Senate Dirksen Building  
Washington, DC 20510

Senator Roy Blunt  
Chairman  
Subcommittee on Labor-Health and  
Human Services-Education  
135 Senate Dirksen Building  
Washington, DC 20510

Senator Patty Murray  
Ranking Member  
Subcommittee on Labor-Health and  
Human Services-Education  
156 Senate Dirksen Building  
Washington, DC 20510

Dear Chairmen and Ranking Member:

As Members of Congress 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 and public health initiatives focused on the treatment and cure of Fragile X and its related conditions.

Mutations of the Fragile X (FX) 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 conditions 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 1,000,000 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.

The Committee's previous support of the important work underway at the National Institutes of Health (NIH) and Centers for Disease Control & Prevention (CDC) has had a considerable impact on the lives of all Americans affected by Fragile X. Historically, the CDC has recognized the significant public health implications of Fragile X and has provided resources to ensure the continued growth and evolution of the Fragile X Clinical & Research Consortium. Tremendous outcomes have already been produced with relatively small amounts of money over the past few years. Current NIH support of FX research is leading the way to targeted treatments which may ameliorate many of the core symptoms associated with FX and autism.

To ensure the rapid translation of ongoing research into near term targeted treatments, we must continue these federal investments in the Fiscal Year 2016 Labor, Health and Human Services, and Education Appropriations bill. Specifically, we respectfully request your support for directives to:

- Ensure efficiency and synergy among the Fragile X and autism research tracks to accelerate translational research toward a better understanding of both conditions and shorten the time necessary to bring effective treatments for both conditions to market.
- Maintain dedicated support for CDC's national Fragile X public health program and continue to support the Fragile X Clinical & Research Consortium.

While we understand the challenges the Committee faces in prioritizing requests, Fragile X has a significant impact on families across generations, on individuals throughout their lives and on communities in every state and district. The potential for effective treatments is within reach. We believe continued support for Fragile X research and public health activities is imperative. We look forward to working with the Subcommittee on this important issue. Thank you for your consideration.

Sincerely,



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Johnny Isakson  
United States Senator



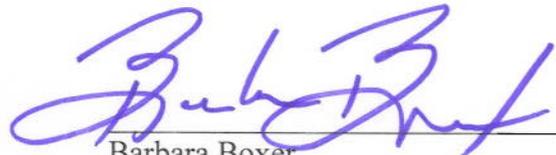
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Debbie Stabenow  
United States Senator



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Richard Blumenthal  
United States Senator



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Barbara Boxer  
United States Senator



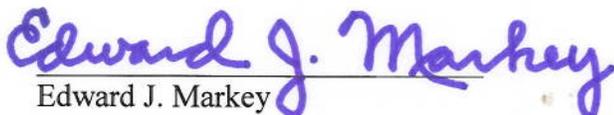
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Richard J. Durbin  
United States Senator



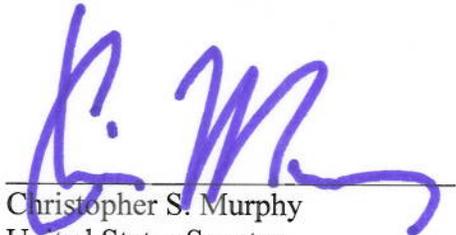
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Kirsten E. Gillibrand  
United States Senator



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Edward J. Markey  
United States Senator

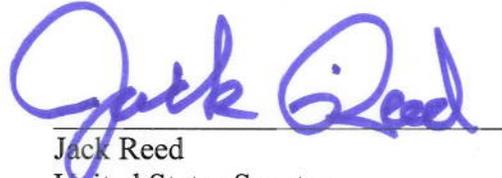


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Christopher S. Murphy  
United States Senator



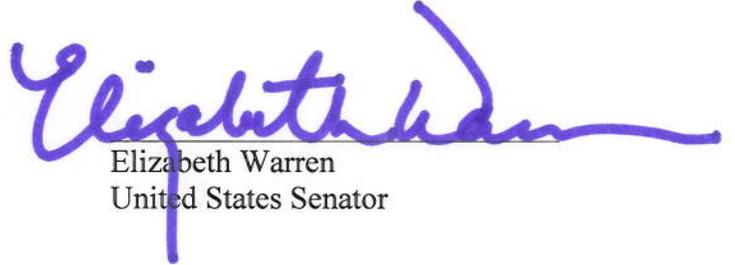
Gary C. Peters  
United States Senator



Jack Reed  
United States Senator



Charles E. Schumer  
United States Senator



Elizabeth Warren  
United States Senator



Roger F. Wicker  
United States Senator