

The Honorable Tom Harkin
Chairman
Appropriations Subcommittee on Labor
Health and Human Services, and Education
131 Dirksen Senate Office Bldg.
Washington, DC 20510

The Honorable Jerry Moran
Ranking Member
Appropriations Subcommittee on Labor
Health and Human Service, and Education
354 Russell Senate Office Bldg.
Washington, DC 20510

The Honorable Richard J Durbin
Chairman
Appropriations Subcommittee on Defense
United States Senate
711 Hart Senate Office Building
Washington, DC 20510

The Honorable Thad Cochran
Ranking Member
Appropriations Subcommittee on Defense
United States Senate
113 Dirksen Senate Office Building
Washington, DC 20510

Dear Chairmen and Ranking Members:

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.

Fragile X-associated Disorders (FXD) are medical and developmental disorders that result in behavioral, developmental and cognitive disabilities across a person's lifespan. Fragile X syndrome results from a single-gene mutation and is the most common, known inherited form of intellectual disabilities and cause of autism. Recent research has shown that the Fragile X protein controls nearly one half of the genes suspected of causing autism. Fragile X mutations are also linked to reproductive problems and early menopause in women (FXPOI) and a Parkinson/Alzheimer-like condition in FX carriers (FXTAS). Over 100,000 Americans have fragile X syndrome and over one million Americans carry a Fragile X mutation and either have, or are at risk for developing, a Fragile X-associated Disorder.

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 impacted. 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 supported clinical trials by multiple drug companies are pointing the way to targeted treatments that may ameliorate many of the core symptoms of fragile X syndrome and autism. Additionally, the Committee's previous support of the important work underway through the DoD PRMRP has had a considerable impact on the lives of all members of the military and their families who are impacted.

To ensure the rapid translation of ongoing research into targeted treatments that will be realistically possible in the near future, we urge you to maintain these federal investments in the FY 2015 appropriations process. Specifically, we request your support for creating greater 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 to bring effective treatments for both conditions to market, and for maintaining dedicated support for CDC's national Fragile X public health program and the Fragile X Clinical & Research Consortium.

While we understand the challenges the Committee faces in prioritizing requests, in light of the significant impact Fragile X has on families and communities across the country, the great potential for effective treatments that is within reach, and the growing body of research demonstrating a close link between Fragile X and autism, we believe support for Fragile X research and public health activities should continue to be a priority.

We thank you for your consideration.

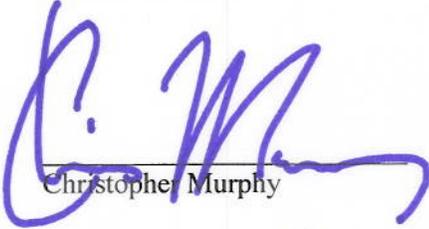
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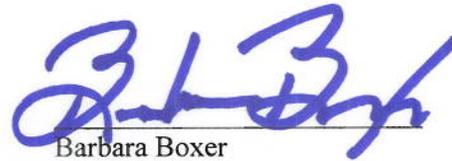
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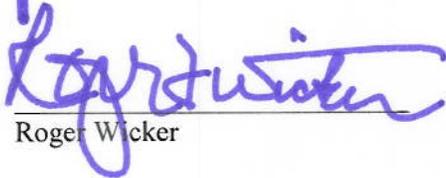
Barbara Boxer



Elizabeth Warren



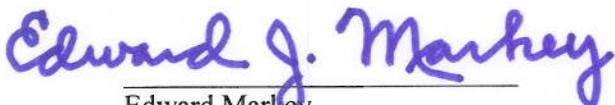
Charles E. Schumer



Roger Wicker



Jack Reed



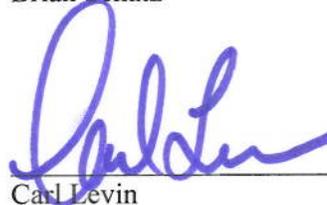
Edward Markey



Brian Schatz



Kirsten Gillibrand



Carl Levin