

United States Senate

WASHINGTON, DC 20510

April 26, 2013

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

The Honorable Jerry Moran
Ranking Member
Appropriations Subcommittee on Labor,
Health and Human Service, and Education
156 Dirksen Senate Office Bldg.
Washington, D.C. 20510

Dear Chairman Harkin and Ranking Member Moran:

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 100 genes suspected of causing autism. Fragile X mutations are also linked to early menopause in women (FXPOI) and a Parkinson's and Alzheimer's-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 Americans impacted by Fragile X. 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 are pointing the way to targeted treatments, which may ameliorate many of the core symptoms of Fragile X Syndrome, and ultimately of autism as well.

To ensure the rapid translation of ongoing research into targeted treatments that will be realistically possible in the near future, we must continue these federal investments in the FY14 Labor, Health and Human Services, and Education Appropriations bill. Specifically, we respectfully request your support for directives to:

- Create greater efficiency and synergy among the Fragile X and Autism research tracks to accelerate translational research toward a better understanding of both conditions and ultimately bring more 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.

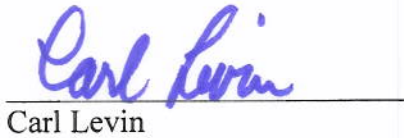
While we understand the challenges the Committee faces in prioritizing requests, in light of the significant impact of Fragile X on families and communities across the country and the potential for effective treatments that is within reach, we believe continued support for Fragile X research and public health activities is critically important.

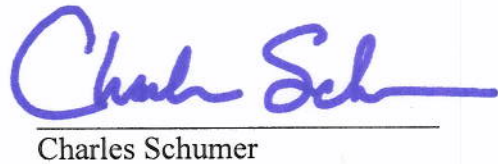
We thank you for your consideration.

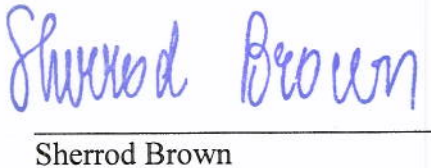
Sincerely,


Debbie Stabenow


Johnny Isakson


Carl Levin

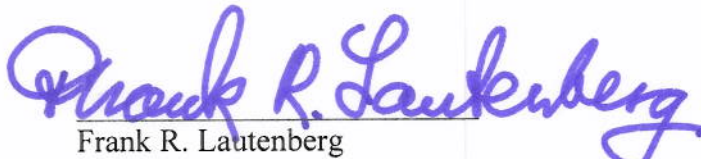

Charles Schumer


Sherrod Brown

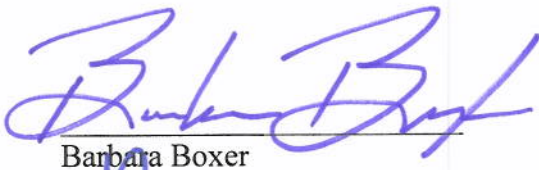

Richard J. Durbin

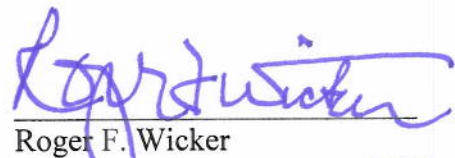

Richard Blumenthal

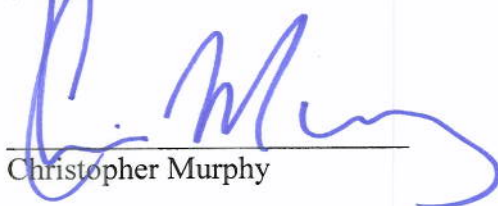

Jack Reed

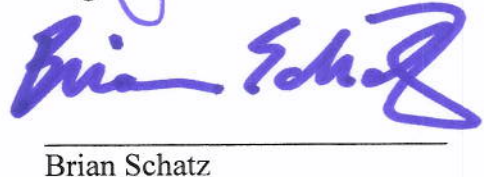

Frank R. Lautenberg


Kirsten E. Gillibrand


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