Congress of the United States
Washington, DC 20515

March 19, 2018

The Honorable Tom Cole, Chairman
Appropriations Subcommittee on Labor
Health and Human Services, Education
and Related Agencies
2538-B Rayburn HOB
Washington, DC 20515

The Honorable Rosa DeLauro, Ranking Member
Appropriations Subcommittee on Labor
Health and Human Services, Education
and Related Agencies
2413 Rayburn HOB
Washington, DC 20515

Dear Chairman Cole and Ranking Member DeLauro:

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 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. More than l00,000 Americans have Fragile X syndrome, and more than 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 and passing the gene mutation to their children.

The Committee's previous support for 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 and the FORWARD Database. Tremendous outcomes have already been produced with relatively small amounts of money over the past few years. Current NIH support for FX research is leading the way to better outcome measures, possible biomarkers, and 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 2018 Labor, Health and Human Services, and Education Appropriations bill. We respectfully request your support for directives to:

- Encourage the continued funding of at least three Fragile X research centers, including the ability to conduct clinical and translational research that directly addresses the needs of affected children and their families;
- 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; and

- Maintain dedicated support for CDC's national Fragile X public health program, the Fragile X Clinical & Research Consortium, and additional extramural research on strategies to promote earlier identification of children with Fragile X, including newborn screening.

While we understand the challenges the Committee faces in prioritizing requests, Fragile X has a significant impact 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,

Gregg Harper

Eliot Engel

John A. Yarmuth

James P. McGovern

Juan Vargas

Salud O. Carbajal

Mark DeSaulnier

Gerald E. Connolly

Lynn Jenkins

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