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FOREIGN RELATIONS

March 25, 2015

The Honorable Roy Blunt
Chairman
Appropriations Subcommittee on Labor,
Health and Human Services, and Education
131 Dirksen Senate Office Building
Washington, D.C. 20510

The Honorable Patty Murray
Ranking Member
Appropriations Subcommittee on Labor,
Health and Human Services, and Education
156 Dirksen Senate Office Building
Washington, D.C. 20510

Dear Chairman Blunt and Ranking Member Murray,

As you and your staff prepare for the fiscal year 2016 Labor, Health and Human Services, Education and Related Agencies Appropriations bill, I submit for your consideration the following suggested report language in the Department of Health and Human Services title:

Centers for Disease Control

Fragile X (FX) and Fragile X-Associated Disorders (FXD) – The Committee commends CDC's efforts to identify and define the population impacted by FX and FXD with the goal of understanding the public health impact of these conditions. The Committee acknowledges significant progress made by the National Center on Birth Defects and Developmental Disabilities' (NCBDDD) Fragile X Clinical and Research Consortium in growing its FORWARD Database and its Patient Registry. The CDC is urged to continue this effort. The Committee also notes with approval the public-private partnership which resulted in the "Future of Fragile X: Setting the Public Health Research Agenda" meeting in 2014 and the resulting FOA which seeks to use longitudinal data to characterize the natural history of Fragile X to improve services and outcomes. The Committee hopes this will facilitate the development of outcome measures for new drug treatments under development. Given the connection between Fragile X (and the FX protein) and autism, the prospect of targeted treatments for both conditions, the overlapping public health impacts and current budgetary constraints, the Committee urges the NCBDDD to explore cross-divisional funding opportunities to accelerate data driven public health research to reduce the public health burden of both FX and autism.

Reaching for the Stars - The Committee urges CDC to build on established surveillance and research methods in order to develop a robust research infrastructure focused on CP across various geographic U.S. regions. Infrastructure of this type holds promise for answering questions about the causes of CP and for identifying opportunities for prevention.

National Institutes of Health

Minority Researchers. – The Committee prioritizes the NIH Director’s efforts to reverse the trend of underrepresentation of researchers from ethnically diverse backgrounds. The Committee encourages NIH to continue to prioritize newly established programs to enhance NIH-funded workforce diversity. Recognizing the historic role of minority-serving, graduate health professions schools in producing minority scientists, the Committee requests a report, within 90 days of the enactment of this law, on how these institutions are participating in the effort.

Minority Participation in Precision Medicine Initiative. – The Committee is aware of the NCI Community Oncology Research Program (NCORP) national network, which provides access to cancer clinical trials to diverse populations in community-based healthcare practices across the United States. The Committee encourages NCI to incorporate NCORP minority/ underserved community sites into the new Precision Medicine initiative as a means of ensuring that minorities are well represented in oncology clinical trials related to this effort.

Fragile X – The Committee commends NICHD for leading the effort to map the molecular, physiological, biological, and genetic connections between fragile X (FX), the fragile X protein, and autism. The fragile X gene and its protein continue to present important insight into discovering the root cause of autism and disease modifying treatments for FX and autism. The Committee urges the NIH to explore ways to utilize funding for FX and autism in tandem to accelerate the pace of research toward identification of the commonality between the two conditions and the development of disease modifying treatments that will reduce health burdens.

Reaching for the Stars - Over 800,000 Americans are impacted by Cerebral Palsy and it is the number one motor disability in children. Currently, there are no identified best practices at diagnosis of through life span, no organized standards of care, no CP registry, and no proven therapy protocols. The Committee urges NIH to work with scientists and stakeholders to develop a 5-year strategic plan for CP prevention, treatment, and cure through the life span with the goal of reducing the number of people impacted by CP overall, as well as improving the opportunity for recovery of those already diagnosed.

If you have any questions or would like additional information, please do not hesitate to contact Jordan Bartolomeo on my staff at 228-5441.

Sincerely,



Johnny Isakson
United States Senator