



Support Fragile X research funding for Fiscal Year 2020. Between the NIH, CDC, and the DOD, the Federal government invests around \$48M/year in Fragile X research. This varies per year, depending on the research proposals funded following the peer review process. Additionally, the CDC's Fragile X program supports awareness among professionals and the FORWARD project, which collects and makes available to researchers data on individuals with Fragile X across the lifespan.

- **SENATE: Request that Fragile X be restored as an authorized research area for the DOD's Peer Reviewed Medical Research Program.** Fragile X was included for the past 10 years, but was not included in FY19. The Appropriations Committee authorizes the medical conditions, disorders, and diseases the program may research through report language each year. Which research is funded depends on the peer review process. The Senate Report for the Defense Appropriations Bill includes the non-cancer diseases and disorders.
- **HOUSE AND SENATE:** Support appropriation bills that include robust funding for the NIH and the CDC, including at least \$2M for Fragile X programs at the CDC.

SENATE: Support the Autism CARES Act (H.R. 1058; S. 427). The legislation will:

- Authorize programs – awareness, training, and research – for developmental disabilities, including autism. They cover all developmental disabilities. The training programs fund distance and in-person training for professionals who treat developmental disabilities, fellowships for developmental pediatricians, and autism-related research.
- Reauthorizes the programs for five-years. They expire at the end of September 2019, so action is needed as soon as Congress returns from recess.

H.R. 1058 passed the House under suspension on 7/24/2019.

HOUSE: Cosponsor the HEADS Up Act (H.R. 2417). The legislation defines individuals with intellectual and developmental disabilities (IDD) as a "medically underserved population" to help increase the services available to them. It provides for:

- Loan repayment and training programs to medical professionals providing care to people with IDD in HSRA's Workforce Development and Training Programs including the National Health Service Corps Scholarships.
- Financial incentives for medical providers to treat people with IDD in the form of higher Medicare and Medicaid reimbursement rates.
- Incentivize new research.
- Federal funding for health centers and public health infrastructure such as Federally Qualified Health centers (FQHC).

Rep. Moulton (D-MA-6) and Rep. Fitzpatrick (R-PA-1) are the lead sponsors. Contact Chrissy Raymond with Rep. Moulton or Joe Knowles with Rep. Fitzpatrick.

HOUSE: Join the Congressional Fragile X Caucus. Contact Sahil Michalek in Rep. Engel's office or Kelsey Griswold in Rep. Chris Smith's office.