



NATIONAL **FRAGILE X**
FOUNDATION



Fragile X Public Policy Priorities

What is Fragile X? Fragile X-associated Disorders are a family of genetic conditions that can affect individuals in a variety of ways. The conditions are all caused by changes in the gene known as FMR1. **Fragile X syndrome** is the most common cause of inherited intellectual disability and the most common known genetic cause of autism spectrum disorders. Symptoms of FXS include a range from learning disabilities to more severe cognitive or intellectual disabilities. Delays in speech and language development are common, as are a variety of physical and behavioral characteristics. **FXTAS** affects mostly males over 50 with symptoms similar to Parkinson's, and **FXPOI** causes decreased ovarian function, which can cause infertility and premature menopause. An estimated 1.3 million Americans are carriers of the Fragile X premutation, and 100,000 Americans are affected by FXS.

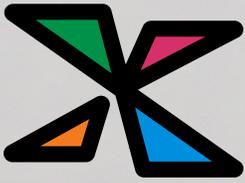
Support Medicaid, SSI/SSDI and coverage for pre-existing conditions – Because FX is inherited, it is a pre-existing condition, so **health insurance coverage for pre-existing conditions is vital**. As people with Fragile X syndrome grow into adulthood, many are not able to live on their own or be employed at a full-time job. Medicaid is the only option for health insurance. **Please don't reduce funding to Medicaid**. It is literally a lifeline for many FX families. Additionally, **Supplemental Security Income and Social Security Disability Insurance** are the federal programs to support those living with disabilities but not able to work, so it is clearly critical for many FX families and those living with FXS and FXTAS who are not capable of being gainfully employed. **Please don't reduce funding and make program changes that negatively affect SSI or SSDI**.

Cosponsor the ABLE Act amendments – ABLE accounts are tax deferred savings accounts, modeled after 529 accounts, designed for disabled individuals who will need assistance providing living expenses as adults. They were enacted in 2014. Please support these amendments:

ABLE Age Adjustment Act (S. 817/H.R. 1874) raises the age limit for ABLE accounts to 46 to allow individuals disabled later in life access to the accounts.

ABLE Financial Planning Act (S. 816/H.R. 1897) allows families to rollover savings in a 529 college savings plan for families who started a 529 before learning of their child's disability.

ABLE to Work Act (S. 818/H.R. 1896) allows individuals and their families to save more money in an ABLE account if the beneficiary works and earns income. Specifically, in addition to the \$14,000 annual contribution cap, an ABLE beneficiary who earns income from a job could contribute from his/her compensation up to the Federal Poverty Level, which is currently at \$11,770 (potentially increasing allowable annual contributions to \$25,770).



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Cosponsor the OPEN Act (S. 1509/H.R. 1223) – The Orphan Products Extension Now Accelerating Cures and Treatments Act of 2017 establishes an exclusivity extension, which would provide an additional six months of market exclusivity for the drug being repurposed for rare disease treatment. The sponsor company must demonstrate that the repurposed therapy is designated to treat a rare disease/disorder and obtains an approved rare disease/disorder indication from the FDA on the drug label. Repurposing drugs is faster, cheaper and presents fewer risks than traditional drug development

CDC and NIH Funding – The CDC and NIH provide critical Fragile X research and awareness programs, including the FORWARD project with the CDC and NFXF, to increase the amount of information on Fragile X patients available to research. **At the CDC, please support \$137.56 million for the National Center for Birth Defects and Developmental Disorders in FY18**, level with the FY17 enacted amount and **\$2 million for Fragile X**, also level with FY17. **At the NIH, please support \$35.184 billion**, a \$1 billion increase over FY17. These are the levels currently in the House Labor-HHS Appropriations bill approved by the Committee. The Senate does not have a bill yet.

Support the DOD CDMRP – The Department of Defense's Congressionally Directed Medical Research Program has provided over \$40 million of Fragile-X associated research. Fragile X is one of the many disorders and diseases Congress has authorized the program to research. Congress directs which areas to research, but grants are awarded on a competitive basis. In the Senate, the National Defense Authorization Act is expected to be debated after the August recess. The bill weakens the program. **Senators: Please support the Blunt-Durbin Amendment to retain the strength of the program.**

More information is available at fragilex.org/advocacy or by contacting Dan Whiting, Director of Communications and Government Relations for the National Fragile X Foundation, at **(202) 747-6203** or dan@fragilex.org.