



The National **Fragile X** Foundation

FOR IMMEDIATE RELEASE

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\$1.6 million agreement to accelerate Fragile X research, inspire hope

WALNUT CREEK, CA — A project to advance research and improve treatments for fragile X syndrome will be funded by a new \$1.6 million, three-year cooperative agreement with the Center for Disease Control (CDC) and others.

The agreement, intended to bring better care to the more than 100,000 affected Americans, is between The National Fragile X Foundation (NFXF), the CDC's National Center on Birth Defects and Developmental Disabilities, the Association of University Centers on Disabilities, the New York State Institute for Basic Research in Developmental Disabilities and the Data Coordinating Center at Columbia University.

Fragile X syndrome is the most common known cause of inherited intellectual disability and the most common known single gene cause of autism.

The effort will advance the core activities of the Fragile X Clinical and Research Consortium (FXCRC). The NFXF initiated the FXCRC in 2006 to advance clinical practice and facilitate coordinated, collaborative multi-site research. The FXCRC has been meeting regularly since its inception to address best practices in evaluation and treatment, including pharmacological, therapeutic and educational treatments, strategies for supporting and enhancing clinic work, and research priorities. The NFXF prioritized its support of a clinics consortium when it realized the body of Fragile X expertise was scattered throughout North America and organizing that expertise would enhance existing and future research efforts while simultaneously making clinical evaluation and treatment more easily accessible to families.

“The fact the consortium has moved from concept to reality to government funding so quickly is a testament to the organization, its leadership and the families that each year travel to Washington, D.C., to urge Congress to support this important cause,” said Jeffrey Cohen, chair, NFXF Public Policy Committee, and father of a son and daughter with fragile X syndrome.

The FXCRC will also address other related conditions such as fragile X-associated tremor/ataxia syndrome and fragile X-associated primary ovarian insufficiency which potentially impact over one million adult male and female carriers in the U.S.

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