



The National **Fragile X** Foundation

FOR IMMEDIATE RELEASE

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NIH plan charts course to better treatments and cure for most common known genetic cause of Autism: Fragile X

WALNUT CREEK, CA — Fragile X Syndrome (FXS) research is moving closer to finding a cure with the recent approval by The National Institutes of Health (NIH) of a comprehensive plan created by a group of leading scientists, parents and advocates.

The Congressional Fragile X Caucus is convening a Congressional briefing to highlight the work of the NIH's Research Plan on Fragile X Syndrome and Associated Disorders and to celebrate National Fragile X Awareness Day in Washington, DC. Leaders of the NIH and Centers for Disease Control & Prevention (CDC), along with leading Fragile X researchers who were instrumental in the development of the plan, will provide insights on the development of the plan, outline key recommendations, and discuss the plan's future impact on the entire Fragile X research trajectory.

FXS is the most common cause of inherited mental impairment, ranging from learning disabilities to more severe cognitive or intellectual disabilities, and is the most common known, single gene cause of autism or “autistic-like” behaviors. Over the past several years, research programs have made significant advances in the understanding of FXS and the associated disorders of fragile X-associated tremor/ataxia (FXTAS) and fragile X-associated primary ovarian insufficiency (FXPOI).

The report recommends 19 goals and 93 objectives to help shape future research in Fragile X-associated Disorders (FXD). Recommendations range from very basic research to applied policy research. Objectives include studying educational and behavioral interventions, evaluating family support systems, identifying risk factors, and looking at molecular and biological systems.

“Implementing a plan of this scope and depth will be an ongoing process over the next few years,” said Don Bailey, Ph.D., distinguished fellow at RTI International (rti.org) and president of the NFXF Board of Directors. “It will require major funding from federal agencies, bright and dedicated researchers who are willing to focus on Fragile X, sustained advocacy, and financial partnerships, but we can see the light at the end of the tunnel. The National Fragile X Foundation fully endorses this plan, and we pledge to work with the NIH and other key partners to make sure that it becomes a living document that truly shapes future research.”

Visit fragilex.org for a link to the full plan.

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