



The National **Fragile X** Foundation

Support-Awareness-Education-Research-Advocacy

We now know that alterations in the FMR1 gene can result in Fragile X Syndrome (FXS), Fragile X-associated Tremor Ataxia Syndrome (FXTAS) and Premature Ovarian Failure (POF). Collectively these conditions may impact over 1.5 Million individuals in the U.S.¹ Each condition has a profound impact on all who are affected, those who are carriers, on their immediate and extended families, the public schools, the healthcare delivery system and thus on society as a whole.

For this reason, it is critical to ensure that policy makers in Washington understand and recognize the impact Fragile X has on our population. It is imperative that the federal government support research and public health initiatives which support the fragile X community. The National Fragile X Foundation advocates for the expansion of federal research and programming efforts at the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDKD), the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Child Health and Human Development (NICHD) and the National Institute of Mental Health (NIMH).

Recognizing the critical importance of this effort, the NFXF has committed the resources to continue to move this agenda forward. The board of directors, staff, public policy committee and a retained Washington advocacy firm all support this effort. This recently culminated in the establishment and congressional funding of the first ever comprehensive public health program focused on Fragile X at the Centers for Disease Control's National Center on Birth Defects and Developmental Disabilities. The program includes surveillance and epidemiological research, newborn and childhood screening, and public/provider education related to fragile X.

In 2003, eleven of the NIH individual Institutes funded over 75 Fragile X research projects. In 2004, federal funding for fragile X research and development exceeded \$20 million dollars. The NFXF will continue to advocate for significant increases in both the number of projects funded and the total amount dedicated to Fragile X.

To further these objectives the NFXF supports a comprehensive advocacy program which culminates each year with an **Advocacy Day** where advocates from around the country travel to Washington D.C. to meet with their Senators and Representatives to make the case for increased funding for Fragile X. Advocates are provided with training and follow-up via telephone, email, letters and local visits continues throughout the year.

To return to the Public Policy and Advocacy page and register as a Fragile X Advocate follow this link: http://www.fragilex.org/html/public_policy_legislative_advo.htm

¹ http://www.fragilex.org/PrevalenceWhitePaper21July05_0.pdf