111TH CONGRESS
1ST SESSION

H. RES. 611

Supporting the goals and ideals of ''Fragile X Awareness Day''.

IN THE HOUSE OF REPRESENTATIVES

JULY 7, 2009

Mr. HARE (for himself, Mr. DELAHUNT, Mr. HARPER, and Mr. BILBRAY) submitted the following resolution; which was referred to the Committee on Energy and Commerce

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RESOLUTION

Supporting the goals and ideals of ''Fragile X Awareness Day''.

Whereas fragile X syndrome is the most commonly known cause of inherited mental impairment in the world;

Whereas an expansion of the CGG trinucleotide repeat in the FMR1 gene—a human gene that codes for a protein called fragile X mental retardation protein—causes almost all cases of fragile X syndrome;

Whereas fragile X mental retardation protein is normally made in many tissues, especially in the brain and the testes;

Whereas fragile X mental retardation protein may play a role in the development of synaptic connections between nerve cells in the brain where cell-to-cell communication occurs;

Whereas there is a unique relationship between fragile X syndrome and autism;

Whereas fragile X syndrome is the most commonly known single-gene cause of autism;

Whereas up to one-half of all children diagnosed with fragile X syndrome also have autism or an autism spectrum disorder;

Whereas over 100,000 people in the United States have fragile X syndrome and over 1,000,000 people in the United States carry a fragile X mutation and have or are at risk of developing a fragile X-associated disorder;

Whereas fragile X-associated disorders include fragile X syndrome, which causes language, behavioral, and developmental disabilities; fragile X-associated tremor/ataxia syndrome—an adult onset progressive neurological condition causing tremors and balance and memory problems primarily in male carriers that can lead to decreased life expectancy; and fragile X-associated primary ovarian insufficiency—a cause of infertility, early menopause, and other ovarian problems in female carriers;

Whereas doctors can accurately identify and diagnose fragile X syndrome, fragile X-associated tremor/ataxia syndrome, and fragile X-associated primary ovarian insufficiency;

Whereas the National Institutes of Health is currently funding a study that will lay the groundwork for screening of all newborns in the United States for early detection of the fragile X mutation;

Whereas increased research into fragile X syndrome can lead to a better understanding of the disorder, more effective treatments, and an eventual cure; and

Whereas advocacy organizations have designated July 22 as ''Fragile X Awareness Day'': Now, therefore, be it

Resolved, That the House of Representatives—

(1) supports the goals and ideals of ''Fragile X Awareness Day'';

(2) supports raising awareness and educating the public about fragile X syndrome and associated disorders;

(3) applauds the efforts of advocates and organizations that encourage awareness, promote research, and provide education, support, and hope to those impacted by fragile X syndrome;

(4) recognizes the commitment of parents, families, researchers, health professionals, and others dedicated to finding an effective treatment and cure for fragile X syndrome;

(5) urges all physicians, health care providers, and specialists to—

(A) learn the clinical signs and symptoms of fragile X syndrome, fragile X-associated disorders, fragile X-associated primary ovarian insufficiency, and fragile X-associated tremor/ataxia syndrome;

(B) use diagnostic, developmental screening, and surveillance modalities to detect fragile X-associated disorders;

(C) test, when appropriate, individuals exhibiting signs of developmental delay or an autism spectrum disorder to determine the status of their FMR1 gene;

(D) gain a full understanding of the genetic implications of all fragile X-associated disorders, and when appropriate, make a referral to a geneticist or genetic counselor to assure that affected individuals and their families are aware of how a fragile X-associated disorder may impact their extended family; and

(E) provide patients diagnosed with fragile X-associated disorders with supplemental information maintained by the Centers for Disease Control and Prevention, the National Institute of Child Health and Human Development, and private foundations such as the National Fragile X Foundation and the FRAXA Research Foundation;

(6) encourages all private and public health insurance entities to provide full coverage for screening technologies, appropriate followup referrals, and genetic counseling services related to the detection, proper diagnosis, and treatment of fragile X-associated disorders;

(7) recommends that the National Institutes of Health and related member institutes fully implement the research plan on fragile X syndrome and associated disorders developed by the Trans-NIH Fragile X Research Coordinating Group and Scientific Working Groups; and

(8) supports increased funding for research into the causes, treatment, and cure for fragile X syndrome.

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