

Dear Members of the Government Administration and Elections Committee:

My name is Nancy Habetz and I am from Fairfield, Conn., supporting the bill to designate September 12 as the Annual Fragile X Awareness Day in Connecticut.

Fragile X is a debilitating condition that leaves its victims with intellectual disabilities and the added burden of severe anxiety that can turn what should be pleasant social occasions into experiences fraught with fear and upset.

You may have never heard of Fragile X - and that is exactly the problem. Neither had we until our son Robert was born in 1969 and showed signs of developmental delays. It took years to find out that Fragile X was at the root of his problems. After taking part in a study group at Yale Child Study Center we were later referred to the Jarvis Center in Staten Island where it was recommended that I (as the carrier) contact my family members and suggest testing. Testing involves a simple blood test and to this point we have learned that eight other family members are carriers of this defective gene.

And this is the problem. With an estimated one in 130 women as carriers, my story will be repeated again and again. Women (and men), who have no idea this defective gene is in their family and getting stronger from one generation to the next, will marry and start to have children unaware of this time bomb, which can suddenly produce a child with such heavy burdens to bear. While we want people to know and understand our children and the challenges they face, it is imperative that we make the effort to inform the public of this condition.