
FRAGILE X AWARENESS DAY TESTIMONY

TO: MEMBERS OF THE GAE COMMITTEE
FROM: BRIAN SWAYNE
SUBJECT: FRAGILE X AWARENESS DAY
DATE: 23 MARCH 2009

Madame Chair/Mr. Chairman and members of the committee, my name is Brian Swayne, I live in West Hartford and I am here to support bill SB 337. I urge the committee to please designate September 12 every year as Fragile X Awareness Day.

My six year old daughter Tess was diagnosed with Fragile X in April 2008. From the time Tess entered pre-school at age 2 and a half she had trouble concentrating, making friends and following directions. We spent a significant amount of money and time with doctors, private schooling, and 3 years with the West Hartford Early Learning Center in an attempt to help her and to figure out why she was having these issues. We tried a variety of approaches, but met with very little success and lots of frustration. Thankfully, the Fragile X diagnosis helped us to turn the corner. Since last April, we have learned about proper therapies and teaching methods that have helped Tess to be a successful kindergartener at Wolcott Elementary School. Looking back, although everyone involved had the best of intentions, our efforts were wasted without an accurate diagnosis. But no one knew about Fragile X: not our pediatrician, teachers at our Montessori School or staff from the Early Learning Center. In fact, once we had the diagnosis, my wife and I found ourselves in the role of educators – bringing brochures, books and DVDs about Fragile X to various meetings and appointments with doctors and teachers.

Raising awareness of Fragile X is critical to help all of those with the genetic mutation so that they can be properly diagnosed. So please consider designating September 12 Fragile X Awareness Day so that a few more kids, a few more adults, a few more grandparents, a few more caregivers will know to consider getting someone they know tested for Fragile X.