

FRAGILE X AWARENESS DAY TESTIMONY

TO: Members Of The GAE Committee
FROM: Marla Wayne
SUBJECT: Fragile X Awareness Day-Bill# S.B. No. 337
DATE: 3/23/2009

Madame Chair/Mr. Chairman and members of the committee, my name is Marla Wayne, I live in Southbury and am writing in support of Bill# S.B. No. 337. I am requesting that the committee designate September 12, as Fragile X Awareness Day.

My son, Justin is 6 years old and has Fragile X Syndrome. We learned of his diagnosis when he was 4 years old. We have been to many doctors and geneticists throughout the country to educate us on how to help my son reach his fullest potential. When I received my son's diagnosis, I searched the entire state for a doctor or geneticist that could help our family understand what having Fragile X meant and what lay ahead for my son. We met with Geneticists at both UCONN Health Center and Yale New Haven Hospital and were given incorrect information and little direction in which to proceed.

We ended up traveling to California, Boston and New York to meet with experts in the Fragile X field. Additionally, we had experts from Denver visit my son's R.E.S.C. school in order to help educate his staff on Fragile X. This summer, we will be going to Denver and Wisconsin to be educated and to participate in Fragile X studies. To date, we have been unable to find a Doctor or Psychiatrist in Connecticut that has the appropriate knowledge to treat a person with Fragile X. We currently travel to Massachusetts to see a Psychiatrist that has the knowledge necessary to prescribe for a person with Fragile X. Additionally, I searched the state for a school that would accommodate the learning style of a boy with Fragile X Syndrome. While my son has been outplaced by our district to a school that agreed to teach him in accordance with his diagnosis, the staff is not educated and does not have experience with Fragile X. This has resulted in a timely learning curve for the school staff and has involved intensive involvement on my part. It is essential that people be made aware of Fragile X Syndrome. The more early screening and education that is made available to all people, the greater potential for those who are affected with this disorder. My son is a loving, emotionally connected child with a sense of humor. He and others with Fragile X deserve to be given as much hope as possible. Prenatal testing paired with proper knowledge on this disorder is important. A statewide Fragile X Awareness Day will help educate all people in our state.

Thank you,

Marla Wayne