

## **Fragile X Awareness Day Testimony**

**To:** members of the GAE committee  
**From:** Madelene Cameron  
**Subject:** Fragile X Awareness Day  
**Date:** 3/23/2009

Madame Chair/Mr. Chairman and members of the committee, my name is Madelene Cameron, I live in New Britain and I am here to support bill S. B. No. 337. I urge the committee to please designate September 12, 2009 as Fragile X Awareness Day.

When I was younger I couldn't understand why my older brother acted the way that he did. I was able to communicate and do the things that young kids did. I could ride my bike, play with other friends and write. It was not until I got much older when I understood why my brother was not developing like I was. Back in the 80's and early 90's no one knew what Fragile X was I did not know what Fragile X was until I was in high school when I got myself tested. I remember thinking to myself what if I have kids are they going to have the same thing. I had gone to Dr. Greenstein, at CCMC and he told me that I was a 50/50 chance of me having a child that would have the chromosome. I think at first I did not want kids because I was afraid.

In December of 2005 I got pregnant with my first daughter Ava. I was worried about the Fragile X being passed on to her even though I did not want to have an amino centsis I was going to except what God gives me. I was under the impression that it would be a lot worse for me to have a boy because of the chromosome of Fragile X would be more sever in boys. When I had my ultrasound in April 2006 I still had no idea what we were having until the baby was born. I gave birth to my daughter in September 2006 and thought I was blessed that I did not have a boy. I then decided to have my daughter checked when she was 2 months old just for my own piece of mind not because she was showing any signs.

I found out in April of 2007 that my daughter has Fragile X however she has a subpopulation of 190. So I'm not sure which one she is going to exhibit. I feel that there should be awareness for Fragile X because there are lots of families who do not understand what it is. Maybe if my parents knew what it was they could have been better prepared for the future. I always try to find out information on different conditions and keep myself educated so when Ava gets older I can explain to her what Fragile X is.