

## **The story of Cathy, born in 1998**

### **Pregnancy, labor and delivery**

I became pregnant with my daughter at age 34, giving birth at age 35. It was an uneventful pregnancy and I did not have any genetic testing, due to my age.

Labor and delivery were challenging. I spent 17 hours in an induced labor. The last several hours, I was on oxygen and my daughter's heartbeat was very closely monitored as it kept dropping. My daughter spent her first week in the NICU due to an infection.



### **Milestones**

During the first year, my daughter's milestones were a bit behind her peers, but certainly not enough to worry about. My daughter crawled at 9 months and walked one week after her first birthday. She would not try something new until she was sure she could master it. She waited to walk until she knew she could do so without falling. She immediately stopped crawling and was perfectly able to walk pretty much from the moment she took her first step. As far as speech, other babies were speaking single words by their first birthday, however my daughter only knew "mama" and "dada". Her speech continued to fall behind her peers.

### **Scary experience at 19 months**

At 19 months, a very scary thing happened. My daughter had just finished a bottle and crawled onto my lap for cuddles. About two minutes later, I noticed she was cold and clammy. Then the unthinkable, I also noticed she was not breathing and was already becoming cold. My husband quickly performed CPR while I called 911. We were able to regain a heartbeat and breathing just as the ambulance arrived. She was very disoriented for several hours after that. She spent the night in the emergency room. Many many tests were performed including an EEG and MRI. There was no conclusive result, however it was suspected she had a seizure.

### **A tall girl**

By age 2, she had grown taller than her 3.5 year old cousins. She was wearing a child size 4 clothes and was much taller than kids her age. We thought this was due to her father's height, as he is 6'3".

### **Delays**

My daughter's development began to show more and more delays. Our initial pediatrician kept telling me not to worry that kids learn at different rates. We switched pediatricians and found one who was willing to entertain my concerns.

By age 3, my daughter had receptive speech skills of a 19 month old and verbal skills of an 11 month old. We also had her tested by an Occupational Therapist and learned that she had Sensory Integration Dysfunction and global fine and gross motor delays. We were able to get her into the school district for help with her speech. She has been seeing the same speech therapist ever since.

### **Five years old: Diagnoses Triplo-X**

Finally, at age 5, while my daughter was getting blood taken for Kindergarten admittance, the pediatrician asked for her blood to be tested for Fragile X as a possible explanation for her delays.

About 6 weeks later, we got the results...Triplo X.

We enrolled her in a regular Kindergarten, however alerted the school of her recent diagnosis. By then, she'd already been in the system for a couple of years getting speech therapy. Of the 113 children in kindergarten at her school, she was the 3rd tallest! (only much older twin sisters were taller.)

### **Special education class**

She was closely monitored in Kindergarten and 1st Grade. Her progress was very slow, even with the maximum amount of pull out for Special Education. Unfortunately, it was not enough and we were prompted to put her into a Special Day Class.

At 2nd Grade, she began attending a full time Special Education class. The results have been tremendous.

She is now in 3rd grade and only 1 grade behind in her work. This is due to very small class sizes and lots of 1:1 help. She's a slow learner, but very bright. She is also very empathetic and friendly (not at all shy!)

She excels at Math and is very slow at reading. Her speech is still delayed (so was mine!), but she is making great progress and will probably be out of speech by age 10. She is in a classroom of 8 children currently, ranging in age from 7 to 10 years old. She is again the tallest.

### **She wants to be a Principal**

When my daughter grows up, she plans on becoming a Principal at an elementary school when she grows up. I have no doubt she will achieve that goal. She knows how to work hard and achieve her goal.

- Mother of an 8.5 year old w/Triplo X