

October 3rd, 2011



Hi Everyone,

My name is Andrea, and I am a 23 year old currently living in a town south of Boston. In September, I went to my first Triple X conference in Holyoke, MA where I met all of the young girls who also have Triple X, as well as their wonderful families. There were a few things that I was unable to bring up and discuss at the meeting that I would like to tell you folks here. I would like to share a brief summary of my history and some resources that have helped me aside from going to therapy, since that was something that was not available for me growing up.

I found out that I had an extra chromosome at the age of 15 as a result of my doctor's concern that I had not received my period yet. After multiple tests, they discovered that I had uterine dygenesis (MRKH) and that I only had one kidney, which was healthy but enlarged to compensate. While having both disorders, I have noticed a few similarities in their symptoms such as issues with my kidney. Also, only until recently have I found any connection of Triple X and MRKH, which I learned from reading the article referenced at the conference by Tartaglia on Orphanet. I found that they each had a major similar attribute: uterine dygenesis. This similarity inspired me to inquire about other connections between the two.

Some symptoms and features that I have, or mostly had in grade school, include: hypotonia, epicanthal folds, tall stature (much taller than my siblings, sprouted faster than my peers in grade school), learning disabilities (reading comprehension, speech issues, etc), anxiety, very emotional, easily frustrated and definitely shy. Although I am sure there were more signs when I was younger, those are all that I am aware of myself. According to my mother, I went through all the milestones at the correct times and it was not until I began school that issues began to present themselves. Since she believed that each child developed at their own pace, it is hard to tell if there were any earlier symptoms present.

In elementary school, I received an IEP and was only told that I had a learning disorder. For that, they gave me reading and speech classes to help. High school was when everything started to click in with each other. After that, I was more aware of my actions and, as a result, school became easier for me. Reading comprehension was still somewhat of an issue for me, but I had taught myself to slow down. I recognized that each word has a meaning and they come together to create a story. As far as I was aware, none of my peers had recognized any striking differences between me and the world.

There were a few things that definitely kept me going through school without any additional help from therapy, which included music and the arts. I started learning how to play the clarinet in the third grade, following after my older sisters. It has been said that music therapy is one of the best therapies, which includes learning how to play. In

college, I learned American Sign Language which I found to be a lot easier to learn than learning another foreign language. Although it requires just as much memorizing, you are physically memorizing the signs as you are practicing. In my opinion, that certainly is more fun to learn with your peers and family. Even though learning Spanish in high school was not a horrible experience, I took more of a liking to learning a more hands on language.

Whether girls who have Triple X have trouble learning or not, everyone should keep in mind that young children are like sponges and are learning much more than we think. Some have said that for Trisomy X girls, the information and knowledge is definitely in there, but has no way of being released. That being said, I believe playing an instrument, dancing, or learning a language requires a different type of learning. For example, different neuropaths are being rewired to comprehend things like new languages.

A good piece of advice for children in school is to find at least one thing to peek their interest. Finding this interest will keep the children motivated and wanting to learn more. Learning to play the clarinet was my motivation. While different instruments and languages have varying levels of difficulty, I strongly believe that we should not stop girls from learning what interests them because you may never know how much they can surprise you. I have heard others have done art or dance, which is rewarding in a few other aspects. I believe that basically any hands on activities could be very beneficial.

In May 2011, I graduated from a local state university. I received my bachelor's in Psychology and loved so many of aspects of that world that I had learned. I am not quite sure what I want to be *when I grow up,* so I am trying out different jobs to find new interests and will go from there. As of right now, I have a full time position as a sales associate in Clarks. The only other job I have had, was working in a preschool/daycare. I definitely started to come out of my shell in the preschool. It forced me to talk to parents, whom may not always be the easiest to speak to and it allowed me to open up as a person to not be as shy as I previously had been.

Lastly, my only question for you guys would be if anyone knew anything more on Premature Ovarian Failure. By going through the testing around age 15, I found out that I have ovaries with fertile eggs. What worries me, however, is the inability to carry my own child. I am afraid I will go through that change and it will be too late to have my eggs frozen for surrogacy at a later date. If anyone knows any information on this, it would be greatly appreciated.

You can find my email adres in the introduction.

Hope some of this helped. Best of luck to all!

Andrea

Tartaglia

<http://www.ojrd.com/content/5/1/8>