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**Governor Hickenlooper proclaims February as Turner Syndrome Awareness Month – this is Alex’s Story…**

February is known for a lot of things: Valentine’s Day, being the shortest month of the year, the month the Broncos won the Super Bowl (!!!), but it’s also known for being Turner Syndrome Awareness month. My name is Alex Boyle and this month is very close to my heart, due to the fact that I am a girl with Turner syndrome.

What exactly is Turner syndrome? Turner syndrome (TS) is a chromosomal abnormality that affects one in 2,000 live female births and out of the number diagnosed only 2% percent survive to term. Statistics have actually changed; when I was born there was only a one percent chance of survival. The defect that causes TS is the missing of one of the X or a partial X chromosome, a female without TS has two X chromosomes. Okay, now that bio class is over I can tell you really what life with this is like.

At the age of two months old my parents were given the diagnosis that would change my life and theirs forever, they were told that their little daughter had TS. Imagine finding out that your child who you thought was healthy and would live a completely ‘normal’ life wouldn’t, actually your child was a one percent statistic and nobody really knew how to advise them how to deal with this.

The information on the internet is misleading and can make you think that things are contrary to what they actually are. It's confusing and scary. I can’t know what it was like from their perspective and up until about the age of eight I was none the wiser to being different. However the way I found out that I had TS was actually quite ironic and humorous in some aspects, My parents and I had gone on a cruise and on this cruise there was a little boy about my age who appeared different to me. One night at dinner he was bouncing around at a table across from us and I asked my parents why he looked different than others (mind you, at eight this is considered highly perceptive), my parents responded by telling me he had something known as Down syndrome. With a nod and a smile I moved on from that...for a solid two minutes before I looked up and asked them if *I* had a syndrome (see, perceptive). Of course, they weren’t going to lie, so that fateful night was when I learned I had Turner Syndrome.

Once I learned about my diagnosis things started to make sense, more doctors’ visits, more surgeries, and more missed classes. I began to understand why everyone else could reach their backpack hook at school but I couldn’t. I didn’t know the extent of my issues, but my parents seemed to know what they were doing so I went along with it.

To this day that’s my mentality, except now I believe it’s “G-d and my parents that know what they’re doing.” Thirteen years after finding out about my Turner Syndrome I’ve gone through the wringer between ear issues that caused me to lose a good chunk of my hearing, getting chronic toxic swelling in my leg known as lymphedema, and ***still*** ending up short. This is only a small portion of my daily struggles because along with not being able to reach the top shelf in the refrigerator or being able to run, the little things like hospital stays and missing out on certain rites of passages (I’m looking at you summer camp overnight hike and freshman year of high school) takes a toll on your soul.

Maintaining a positive outlook is so important, but it’s not always the easiest thing. I can’t tell you that I deal with my Turner Syndrome, because I honestly don’t. Every day I have to get up and make the choice to fight, and it’s not always so strong. My faith in G-d and my relationship with my friends and family keeps me going, they’re my strength and I will forever be grateful. I think that’s the case with anything in life; no matter who you are and what you have, having something to believe in *and* believing in yourself is so highly important.

Turner Syndrome is not a black and white disorder, it affects every girl in different ways, but at the end of the day we are all connected by a bond that very few can understand. It is with my sincerest hopes that I did the community proud and was able to inform everyone just a little bit about Turner Syndrome and what we have to go through. We are smart, strong, beautiful, and have a thing for being very persistent in the pursuit of our dreams. We can do anything we set our minds to, just sometimes in different ways. We are special and unique and will be the people who help change the world.

I am proud to call myself a girl with TS, but I won't let it be the defining fact of who I am. Just as in any good story, there are character traits, and in my story of life, this is just a minor part.

This is a taste of my life’s story thus far, it’s being written every day and I can’t wait to see where it goes! - ***Alex Boyle is a student at Metropolitan State University Denver and an active member of Turner Syndrome Colorado***

***Turner Syndrome or TS is a non-hereditary genetic disorder that exclusively affects girls and women.****It occurs when one of the two X chromosomes normally found in females is missing or incomplete.* ***TS is considered a rare disorder and occur in 1 of every 2000 live female births.***

* *It is estimated that only 1% of fetuses with just one X chromosome survive to term.*
* *Approximately 10% of all miscarriages are due to TURNER syndrome.*
* *There are over 71,000 girls and women living with TS across the United States*
* *Turner Syndrome primarily affects the 2nd X chromosome and in turn is reflected in the secondary sex characteristics of females.*
* *The most common feature of Turner Syndrome is a short stature.*
* *The average height of an adult TS woman who has not received human growth hormone treatment is 4’8.*

***COMMON MEDICAL CONDITIONS INCLUDE:***

* *Delayed Puberty \* Heart Defects \* Hearing Loss \* Learning Difficulties with normal Intelligence*
* *Kidney, Thyroid and Liver Concerns \* Frequent Ear Infections \* Puffy Hands and Feet \* Infertility*

*Due to the complex nature of TS, local Colorado families worked tirelessly with health care professionals to create a comprehensive level of care through the* ***eXtraOrdinary Kids Turner Syndrome Clinic at Children’s Hospital.***

***The Turner Syndrome Clinic is a multidisciplinary clinic designed to address the medical, developmental and psychological needs of girls and adolescents with Turner syndrome. Providers on the Clinic Team include:***

* *Geneticist and Genetic Counselor - Developmental-Behavioral Pediatrician - Cardiologist Endocrinologist - Adolescent Gynecologist - Neuropsychologist - Clinical Child Psychologist*
* *Referrals to other specialists as needed*

***Early detection is the key in getting the necessary medical care for all girls with TS. All girls with slow or delayed growth should be referred to a pediatrician for a health assessment, including the consideration for TS. For more information contact Turner Syndrome Colorado.***

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