

Written may 2009

My trisomy X "story".

I would really like this to be published, especially to show up that nurse who told my parents i would be an invalid, and a curse, and a constant bother to my brothers.

I want other people to know that its not the end of the world. And that any prospective parent shouldnt even contimpliate abortion. because i know thats what that nurse wanted my parents to have. I know thats what my family wanted them to do. And i'm not sure everyones parents or prospective parents have 2 chemistry and biology degrees backing their decision like my parents did.



I want my email published so people can contact me.

My name is Stella Spencer, i'm 19. Thats nearly 2 decades of trisomy x.

I've decided i wanted to tell everyone about my story because maybe then someone one will say "well yeh, thats me too." I'm going to type this straight into the email with no word processor because then you can see what my real writing is like not my spellchecked writing.

My parents had me tested before i was born because they had other children with genetic problems. And ive been told they pretty much decided to have me regardless of the results (and arent i glad about that).

Both my older brothers are totally fine, i had a third older brother who i died of what i believe was Edwards syndrome. And a sibling prior to me that also died. Both at birth. My mum and dad where 45 when i was born which also is believed to have contributed. My brothers are much older 35, and 33 they both have children, one has a little girl and so far no genetic abnormalities. Which means im a one off, just like the genetisis said.

My mum told me i had trisomy x when i was 8, and i was playing on her bed and looking out the window and i took it in but ten minutes later totally forgot.

When i look back now i realise so many things where signs of my trisomy x.

At school i was always very shy. i got shoved to the back of the queue, and every single parent teacher night i was told i was "quiet in class".

Reading:

In the first year of primary school i remember being dropped from the top reading class to the second reading class and replaced with a boy named Ryan. This really damaged my confidence for the rest of my school life, and i still hold that against my teacher.

Reading wasnt my strong point. But i hated being labled "slow". It wasnt that i was slow, it was that i found the "out loud" reading really difficult. My throat seizes up and i cant talk and my voice goes whispy and all the words come out wrong and i just pick random bits of sentences and throw them together. then i would be laughed at, and my confidence would go down again. Now i think it will take years. I mean i was only 5 when i was told this and i still havent got over it.

Writing:

I was a really slow writer, all the time and i ccan never make my hand writing consistant, sometimes its squidy and round, some days its slanted left, sometimes right. I never

know what its going to be like. To the extent i was acused of cheating and getting osmoene else to do my work at school. I had to show them writing to prove that was just me.

I onyl got support in my last 2 years of school after a long running battle to "prove" i actually had a problem and that i wasnt just "lazy" or "unmoativated".

Somethings i notice myself, when i write "M" it will come out as "B" and vice versa. When i try to write "Show" it becomes "you".

I think thats something i notice a lot. getting words mixed up.

My parents first noticed it when i would say "abulance" instead of "ambulance" or "cone pine" instead of "pinecone"

Friends:

i find it easy to make acquaintances but hard to make friends, people like me, but i cant stand big groups. i never go out clubing or partying. i find being with more than 3 people awkward and starts me panicking.

I make male friends better than i make female friends. Infact it is on my "to do list" to make a female friend. Boys are so much simpler and enjoy the finer things, such a tree climbing.

Physical:

(I've lost the thread of what i was writing *typed liking instead of writing*)

As far as physical aspects are concerned i believe i may not be so effect, i have hypermobility. Mainly problems in my knee and hip joints that constantly ache and require a raft of painkillers. My doctor has been quite good about this I often dislocate my fingers, which can hurt a bit but i've made it a party trick now. I also should mention i am a tiny little 5"3, i stopped growing when i was about 13! until then i was the tallest person in my class, at one point in primary school i couldnt go to school growth pains where so bad. looks like the joint problems are progressivly getting worse with age. Its upsetting being only 19 and already have knees like an 80year, and all the 80year olds i know are skipping and dancing around and i hobble. Its a bit annoying, but im not in a wheel chair and i go horseriding, (which im pretty good at too).

I wear glasses but the theory is i spend too much time on the computer. I have poor eyesight which is what is thought to contribute to reading difficulties. But i dont think so. I get lamp posts and trees mixed up, no word blurring.

I also have, and this has never been proven to be conctected to TX but i once spoke to a girl with TX who had a similar problem. Im throwing this one out there because theres no research on it, its pretty embaressing, but we're all girls here.

I have a "bladder problem" that causes me to feel like i need to go to the toilet but i dont actually need the toilet. This started when i was 7 and progressivly got worse to the point now where i have emailed some of the top experts in the world and baffled even them. This may have nothing to do with TX, but what if it does? ITs embaressing right? talking about problems like that, i never spoke to it outwith the doctor or my family so who is to say its not a TX sympton.

Its incredibly uncomfortable but not painful. it ruins my daily life to the extent i couldnt go to school./now cant go to work. And the only cure is either a big dose of codine or a hot shower.

The other thing i notice about TX is eratic periods. i first got them when i was 10. Youngest in my year.

(This is getting very long, if i was me, which i am, i wouldve lost interested by now and be skim reading it) TX doesnt stop you having sarcastic humour.

I would like to share some TX positives with you.

One dont let this IQ crap (am i alowd to swear?) get you down I have a tested IQ (UK test) of 129! it was done at school and my head teacher said "why dont you use your IQ!"...well i do i just dont use it for academic things, or spelling. :)

You can say that its been shown, but my parents really helped me know things about the world. Thats what IQ is about knowing and understanding. And i may fail a little at those "look at this shape" test, but otherwise a lot can be based on remembering simple facts, Listing things (i love to list) etc.

I decided not to go to university, despite being qualified to do so. but now im thinking about going back.

At the moenent i work as a bookseller, for a big name brand. I have all the titles in the shop memorized based on the colour of their spine. So dont say that TX isnt somehow useful.

I'm very artistic (not to toot my own horn) And have considered a career in art. And a little suprise. Englsih is often one of the hardest subjects for TX. But it has become my centre subject. i now wish to write a book. and as an editor i met said. The editors job is to correct your spelling. as long as you have a creative mind and can teach yourself to write then theres is nothign to worry about. lost of authors have worse problems than you."

I learned to play the violin when i was 4.5 years old, and while i never aspired to succeed, i did the best i could be bothered doing.

Heres a little run down of my school grades *for those worried parents, and girls taking their exams*

These are scotish grades i'll try to write the english equivelent next to them

Standard Grade (o-level/gcse) 1 being highest 7 being an utter fail.

Chemistry	1
English	1
Business	1
Biology	2
Geography	2
Art	2
Maths	2
French	3

Highers (A-level) A being highest, D being a fail.

English	C
Business	C
Geography	A
Chemistry	D (i couldnt do the equations)
Art	C
Relgion	A

Advanced Highers (upper A levels/6th year studies, First year degree or Diploma)

Art and Design	C
English	C <<< look girls english...supposedly our evil arch nemisis...is..is...

I hope that my rambling, disorganisation and spelling errors inspire some confidence in parents and TX Negotiators, i say negotiators because we are constantly negotiating between being a blessing and a curse.

I am aware there are people out there a lot worse than me, but there are disabilities and then there is TX and lets face it girls, whats so bad about a genetic condition that makes you more beautiful :P

I want to make it my job to inspire confidence in TX girls, and i know i dont have it all good, and i get pretty depressed sometimes. Tending to get over emotional but i've done it so many times before, i know i get over it. My main aim is to make sure everyone understands that TX can be countered in the enviroment we live in.

I also want to offer my support as i suffered greatly at the wrath of other bolder girls. Who tormented me for 4 years, not as bullies but as so called friends, and i get a feeling that this is a big problem in TX, because we ARE shy and we get pushed to the back all the time and let people stomp all over us. Teenage years where really hard, *still is a teenager technically* I mean school. Especially with no help at all. and with the ratio being. 1:1000, i have to think there must be a lot of TX girls out there who dont know it, they just get written off as stupid! I always wonder how many TX's we'd find if we could test the so called "drop outs" in schools. Or other dyslexic girls. I was only tested because of my mums age and history.

If there are any girls who want to talk to me about it, i mean the ones who are still going through it all i really want to help. Because despite telling myself on a frequent basis the end of the world was nigh, it has yet to happen.

I'm also thinking about studying biology with intent to move into genetics, but who knows, inever thought i'd be a bookseller or excell at english! XD

If anyone wants to here more brief ramblings/indepth ramblings (do you have the concentration i don't) then I want people to email me: rawfiche@hotmail.co.uk.

Brief update may 2010

I have recently been diagnosed Asperger.