



Parley

Parents And Relatives
Listening and Empathising
with You

Ali's Story

First thing i would say is being a parent is the most wonderful thing in the world but when you have children with disabilities it can also be the hardest thing in the world too.

As a child from the age of 9 I was always complaining of general joint pains which was put down to growing pains, i excepted this as the norm and got on with my life and the pain to then at the age of 20 i fell pregnant with my 1st baby, and 9 months later after a uneventful pregnancy we were blessed with a lovely baby girl, Megan. i fell pregnant again very soon after having Megan only this time the pregnancy was so much different, i suffered from pains really badly and at my 21 week scan was told i had grade 4 placenta privia and the chance of the placenta moving before delivery were very low, prior to this i had bleeding through out the pregnancy and had been told after a third major bleed i would have to be admitted to hospital until delivery, well this third bleed came at 28 weeks and i was admitted to hospital for the foreseeable future and faced the next 8 weeks in hospital (they were going to do a section at 36 weeks, well i didn't get to 36 weeks and after waking very early one morning in a pool of blood i knew something was seriously wrong, i was rushed to theater where i was found to have had a potentially life threatening eruption of my placenta and my baby was delivered at 32 weeks, another baby girl weighing 4lb 8oz we called her Millie.

Megan and Millie are very very close but as they were growing we noticed with Megan she was delayed in alot of aspects of her development, she didn't crawl and nor did she walk till she was 22 months old Millie was the same only when Millie tried to stand she was scream in pain, like her sister she never crawled but walked every where on her knees.

we bought our concerns to our gp who in turn referred our eldest daughter to our local hospital, they didn't refer our youngest as she was still not classed as being delayed as she was still small and they put every thing down to her being premature. we were soon given a appointment with the pediatricians who did all the normal bloods etc which came back all clear and so was referred to a rheumatologist. we saw him and he confirmed that there was indeed something wrong with our daughter and much to our shock myself too and all those growing pains were indeed not growing pains but a condition called Ehlers Danlos syndrome a connective tissue disease which causes global joint pain, frequent dislocations, fractures and subluxtions as well as a whole host of other probles including cronic fatigue syndrome.

Millie has just at the age of 4 been officially diagnosed with the condition and suffers more than her elder sister, both of our girls are under Great Ormond Street children's hospital for there condition and attend a intensive 2 week physio course each year as well as check ups every 4 months, Megan as a result is a part time wheelchair user but because the condition has effected Millie's spine she is a full time power wheelchair user as she is unable to be a manual chair user because of the daily dislocations to her shoulders.

this is a life time condition with no cure and will progress to osteoarthritis later in life the only thing we can do is treat the pain with medication and do a daily physio programme with our girls.

In 2008 we had our 3rd (and final) baby again born at 32 weeks this time due to PROM as a result of my Ehlers Danlos syndrome she weighed a tiny 3lb 7oz but done well apart from slow blood clotting at birth, but we were told this had corrected itself by the time she got discharged form hospital but it wasn't so, at 11 months old i caught the top of her finger while cutting her nails and it bleed for nearly 5 hours and was the smallest of cuts, she has since been referred to London for further tests but they have so far found she has multiple factor deficiencies in her blood but more tests are being done at the moment we are also waiting to see if she has the same condition as myself, Megan and Millie.

Life can be difficult for us but we have great support from people around us, we just live in hope that one day there may be a cure to this painful yet invisible condition.