

Let's start at the very beginning

Sent in by Genevieve Hundermark

After two years of battling to fall pregnant and a mere two visits to a Homeopath, we were over the moon to discover that we were finally pregnant! My pregnancy was wonderful and I loved every minute of it. Besides for a little exhaustion, it was a breeze.

Jessica Muraour was then born on 23 May 2006 by elected caesarian section as our gynae explained that Jessica's head was too large for normal delivery. The doctors did battle for a little while to get her out as she had already lodged into the birth canal and I had to be cut an extra three centimeters on either side!

Jessica however was perfectly healthy and her Apgar Score was a 9/10. Besides for mild jaundice and a little skin reaction to any polyester clothing, she was perfect. At around six months old when we went for her immunizations to our local baby clinic, the sister noticed that Jessica did not have the neck control that a baby of this age should and suggested that we have an assessment done at a physiotherapist.

We took Jessica for an assessment where it was discovered that Jessica suffered from Hypotonia / low muscle tone. She also did not like being on the floor much and preferred the comfort and secure feeling of being in her pram. If we lay her on the floor for play time she would almost fold her body into a 'banana shape' as though it was too overwhelming for her.

We then started physiotherapy once a week and shortly thereafter we started occupational therapy too. During her physiotherapy visits, it was also discovered that Jessica's eye sight was not developing as it should, that she perhaps saw everything as one and could not distinguish between items near and far. We worked hard on this by training her eyes with different colour papers and items. This seems to have rectified itself and her eye sight is just fine now.

When Jessica was about 9 months old, our peadiatrician advised us that we take Jessica to a neurodevelopmental specialist as there are many underlying conditions associated with low muscle tone. The specialist noted that Jessica was fascinated with her hands, that she had a normal muscle bulk however her muscles were soft, that she had no lateral support reflexes as yet and that she was not making good eye contact. Jessica then underwent many blood and urine tests, most of which would come up as inconclusive or the samples would be sent to the lab incorrectly and would have to be redone, it seemed that Jessica had been turned into a pin cushion.

At 12 months old, we were told to take Jessica for a MRI scan which was a very traumatic day for her, she was very miserable once she came around from the anesthetic. This identified that there were some abnormalities with an asymmetrical appearance to her brain which may be due to premature sutural fusion. It was suggested to redo the MRI scan after the age of two which we are hoping to do this year.

We were then advised by our paediatrician to take Jessica to a geneticist to rule out any kind of syndrome and although he could identify one or two anomalies on Jessica, none related to a specific syndrome.

It was then suggested that Jessica may suffer from a condition called Hawkinsinuria, which is an inborn metabolic disorder whereby too much protein is actually toxic to Jessica as her body cannot break down the Tyrosine in protein which then builds up in her body. We then visited a dietician and Jessica was placed on a protein restricted diet, she became an instant vegetarian! Luckily she took well to this and absolutely loves her food.

She started a whole cocktail of anti oxidants, vitamins and minerals to clear out any toxin build up and maintain her ability to clear out any future build up. Jessica subsequently lost quite a bit of weight also taking into consideration that she was not moving around much however we seem to have that under control now, thanks to her dietician.

After follow up samples were sent to Cape Town to better identify if Jessica did in fact suffer from Hawkinsinuria, it was stated in their lab report that although she had traces of the components of this disorder in her system, there was no supporting evidence as normally these sufferers fail to thrive, have limp hair etc. whereas Jessica was growing steadily. They did however not want to completely exclude this condition, so basically we were in a catch 22 situation.

At this stage, Jessica was rolling over, sitting well however did not know how to lie back down so she would just throw herself back and therefore we could not leave her alone whilst sitting. She could also pass objects over her midline and was in a standing frame to assist her in putting pressure through her legs and our biggest thrill was that her nanny had taught her to hold her own bottle!

We were then introduced to Genevieve through a relative. We arranged to meet up with Genevieve as she was an instructor of BabyGym which apparently was very beneficial to baby's with or without developmental delays.

Genevieve gave us an overview of BabyGym and explained to us that we needed to go 'back to basics', how vital 'switches' in the brain should be 'switched on' during the birth which often are simply not. At our first appointment we were taught how to do a specific massage that imitated being born and would assist with her brain making these crucial connections.

It is wonderful, because it is so 'hands on', it is the perfect bonding time with mom / dad and baby. It took Jessica a little while to get into the touching as she was a bit tactile but after a while she really started to enjoy it. We then started to vary the speed of the massage, fast in the morning and slow at night. The evening massage was great as it seemed to almost get her in the mode for sleep! And for the first time, I can actually say that Jessica was making perfect eye contact.

We then proceeded to work on her senses and reflexes and eye coordination through the next BabyGym sessions. Things that are so vitally important for a baby's development. We then moved onto working on her neck and core strength and after a lot of hard work from Jessica, we

were amazed at the strength of her neck muscles. She is able to if we do pull ups, completely lift her head and shoulders off the floor, all by herself!

Currently we are busy with strengthening her core muscles where some of the exercises include bouncing and rolling around on a gym ball which Jessica loves. She has also started school in a special needs class this year and has adapted very well.

Although we are happy with the way Jessica is constantly improving, we do still have a need to have definite answers about her condition. We are hoping to go to Australia toward the end of the year as we have made contact with the director of a lab there who specializes in more advanced testing of metabolic disorders such as what Jessica may have.

We persevere with the massage and all the other exercises that are shown to us, it has become part of her daily routine. She is constantly amazing us with her improvement. We know it is a long road but with the invaluable knowledge that has been provided to us from Genevieve, we are so ready for the journey!