

# Luke Legemaate

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[To view a short video of Luke's story click here](#)

## Chapter 1



Hi, my name is Luke. I was born on 21 December 2005 at 37 weeks 4 days, via caesarean section. My mom had a difficult pregnancy, suffering from hypertension and nausea throughout. My doctor was amazed at how endemitis (swollen) and floppy I was at birth. My apgar was 3/10 and then only 6/10. I weighed 3,88kgs. The doctor immediately ran tests to see what she would find out and besides having low protein, nothing seemed out of the ordinary.

I lost 700 grams in the first 4 days of my life. This was all fluid. Everyone was very worried about me especially as I would not suck and because I had a floppy airway. I was tube fed.

My mom, who is a teacher, knew of the book Baby Gym by Dr. Melodie De Jager and quickly read it whilst sitting in the ICU with me. She immediately started doing strange things to me. She rubbed my ears at every opportunity, kept her finger on my navel whilst rubbing my bottom lip, rubbed my top lip and held her finger on my coccyx and did something she called the cross curl. She massaged me before every feed, rubbed me with all sorts of different textures and stimulated me with music and black and white pictures. She was also nice enough to let me sleep a lot.

On the 27 December I had a CT scan. This showed that I had cerebral atrophy throughout the brain, in other words brain damage. The doctor said that she could not predict how I would develop. I may be just slightly brain damaged, cerebral palsied or severely brain damaged. I had all the tests imaginable, chromosome and metabolic etc. and they all came back normal and consequently did not explain my

condition. I am going to have an MRI scan done in June to give us more information. My mom and dad were initially very upset but quickly decided with God's help they would continue to do what they could for me. I came home on the 6 January with my feeding tube and was still very floppy. Losing the fluid had helped a little.

My mom, dad and granny worked tirelessly on the program they had worked out for me with the help of Dr Melodie de Jager, as well as the paediatrician and the physiotherapist. Mom spent a lot of time stimulating the sucking reflex and on 26 January my feeding tube came out as I was taking my full feed of breast milk via the bottle. Mom has continued to express, so I get the yummy breast milk.

I started to smile at two and a half months. I am now four months old. Everyone's concern is that at 4 months I still do not have adequate head control, although they say I am improving all the time. I now have to see an Occupational Therapist who has given mom more exercises to help me. I get to play under my play gym, listen to music and mom and nana like to "sing" to me. I have two favourite toys, a panda and zebra.

I recently had a hearing test as I saw no reason to make a noise when I was so well looked after. This worried mom a little. The audiologist said I can definitely hear through the left ear but she got no response from the right one as there was a lot of fluid behind the ear drum. Mom continues to rub my ears all the time. She says we will surprise everyone with what I can achieve one day. She is convinced that all the exercise and stimulation she does with me, primarily from the book Baby Gym have helped considerably. Even the paediatrician says I am catching up and am almost like a "normal" baby my age.

If you are like me, needing a little extra help to get started in life, ask your mom to buy the book, Baby Gym and get to work on stimulating you. Maybe you will like it as much as I do. My mom and dad are very positive people; they believe they can do anything with God's help and a lot of hard work.

## Chapter 2

Here is some feedback of our visit to Durban last week with Luke. Based on Luke's history, we were advised to have an MRI and an EEG. The MRI looked at the physical condition of the brain while the EEG is a study to see the response of the brain to certain stimuli to ascertain fitting etc.

The amazing thing is that both the MRI and EEG came back clear in terms of problems identified. The MRI did not show any fibrosis bands in the brain, indicative of brain tissue dying. This rules out the possibility that either oxygen starvation or any "birthing" issue caused the Luke's problems

The MRI also showed that myelination is occurring throughout the brain (the process by which the myelin sheath is formed around the nerve fibres); in other words the stimulation that Elizabeth (Janet's Mom) and Janet are doing is resulting in brain growth. The degree of myelination is in keeping with children at a similar age. The fact that myelination is occurring simply confirms the growth that we have seen externally over the last few weeks with Luke responding to people and even smiling. Even the head control is improving and at times he really gets excited and

arms and legs fly! The myelination also rules out the possibility of any white brain disease as this would result in regression rather than improvement

The paediatrician today estimated Luke's developmental age to be about 4½ months which means he is only 1 month behind. (This is not bad in lieu of the fact that i.e. was born 1 month early and babies only [catch up] when they are 5 years.)

The fact that he still battles to hold up his head as a baby his age would, made her put his head control at about 3 months. It is obvious that he has low muscle tone and the reasons for this are still not clear. We will continue to work hard on improving this. As to his mental ability, we will only know this as he develops.

It is clear that the paediatrician is puzzled by the results and we reviewed with her again the issues that Luke faced at birth. She is sending the results of the MRI to the only Paediatric Neurologist in Johannesburg for another opinion

It is clear that this sounds great, and we are really hoping to be able to declare that Luke is clear and God has healed him of whatever the issues are. But we have only reached the point of what is NOT a problem. We will continue with Luke, praying that the healing is complete, but in the meantime continue working on his development and praying for wisdom to do the best for him.

God bless and lots of love

### **Chapter 3**

Can you believe that I am nine months old next week? I heard mommy say that she is really proud of me because I am able to sit on my own for a few seconds before I get the wobbles. I spend about eighty percent of my time on the floor and really enjoy rolling around. I know the song "ten in a bed" and know to roll when the little one says "roll over". I have learnt to "talk". It took me awhile but I now experiment with all sorts of sounds but I still like to listen when mommy reads/talks to me or a tape is put on for me to listen to.

Since I had the MRI in June and this showed that I have normal brain development and normal myelination throughout the brain we have all been so encouraged. This is especially encouraging as the results are so different from the initial CT Scan results when I was one week old.

My mommy and Nana still make me do lots of Babygym exercises although I have graduated to some new ones. Mommy says these are to help me sit and crawl properly. I know mommy sometimes worries when she sees other babies my age but she quickly looks back at all the things we can now do together and feels better.

Mommy says that I am her gift from God, which makes me feel special. We are going to work hard to give me the best possible start in life. Mommy is always telling people that using the Babygym programme consistently and with focus has made all the difference.

Thank you, Aunty Melodie for your input into my life.

## Chapter 4

Wow! What a year 2006 turned out to be. First the shock of Luke's condition and prognosis, then the rush to find ways to help him, then THE WORK to help him, AND THEN THE REWARDS! From very limited possibilities at birth and a diagnosis of cerebral atrophy and most probably cerebral palsy, to a MRI result of a normal brain and normal myelination at six months to a responsive strong big baby at 13 months. This is all because we serve an awesome God and have been guided by so many people to persevere, despite feeling very tired and discouraged at times.

Luke has gone from a floppy, unresponsive baby to a delightful, very responsive, very active big baby who brings hours of joy and entertainment to the whole family.

His muscle tone is vastly improved and his head control almost normal although his head still lags to the side when he is very tired. He sits beautifully now and should he bend forward to pick something up can right himself into a sitting position. Crawling is another thing. Luke has devised his own method of getting around which is moving around quite rapidly on his back by arching his back and pushing himself forward with his feet. He now has a couple of bald spots on the back of his head from all the wear. As you can imagine, although we initially found this amusing, we desperately want him to crawl properly. Time on the floor on his tummy, his exercises and rolling over a blow up tube are all a matter of course in this household at the moment.

We are really encouraged by his interaction with us all. He points to items (especially food) that he wants, points out the individuals in our family if asked to and just recently started saying (dada). He loves his books which my mother religiously reads to him each day and loves to touch all the characters in them. Most of these books are those with textures in so we always encourage him to feel these with both hands.

There is still a way to go and we do not know to what level Luke will function in the future, but we are very optimistic. Luke's pediatrician does not believe that Luke would have developed anywhere near how he has without all the stimulation he has received. The success of Luke's life has taken a concerted effort on the part of the occupational therapist, physiotherapist, pediatrician as well as a good knowledge of BABYGYM. If I think back to those first few days after Luke was born, I will be forever grateful for the support and encouragement we received from Melodie De Jager (I had known her for a couple of years) and the support (an surprise) from the NICU staff (they could not say no to this determined mommy) when I started to massage Luke's ears and exercise him.

We trust that Luke's success will be an encouragement to parents to persevere and never give up on the special gifts they have been given, no matter what the prognosis.

## Chapter 5

Luke is almost seventeen months old. He is now crawling albeit a little unsteadily, standing and attempting to totter from lounge table to chair.

He loves (reading) and associates the pictures with the real thing e.g. looks at the clock in the book then looks for and points to the wall clock in the room. He does this for a number of items. He also has a healthy appetite (he eats anything!) and knows exactly what is edible or not, pointing these out and opening his mouth for food. He say (es) for yes, dada and mommy, adad for his granddad, nana and (boo) for book. He has become so much more vocal in the last month or two and we can see his lack of mobility is causing him immense frustration.

I believe Luke's lack of crawling and walking has been a result of low muscle tone in his upper body. We have worked tirelessly on this and are grateful for the improvement but we know there is a long way still to go. Luke is behind other children in a physical sense but appears to be a wide awake little boy.

We look forward to seeing the little boy he will be

## Chapter 6

### Dear Aunty Melodie



Can you believe that I am already three years old? Mom says I am a little cherub! In September the doctors diagnosed me with a funny thing called Prader-Willi Syndrome. This explains some of my symptoms at birth and my development so far but not all. No one can explain why I had cerebral atrophy at birth and at six months, normal brain development and myelination.

Anyway Prader- Willi syndrome brings with it a number of interesting characteristics. The following definition is taken from the Medical Alerts booklet of the PWSA (USA) association.

“It is a complex neurobehavioural genetic disorder resulting from an abnormality on the 15<sup>th</sup> chromosome. It occurs in males and females equally and in all races. Prevalence estimates range from 1:12000 to 1:15000 . Incidence in Newborns is unknown. PWS typically causes low muscle tone, short stature if not treated with growth hormone, cognitive deficits, incomplete sexual development, problem behaviours and a chronic feeling of hunger that, coupled with a metabolism that utilizes drastically fewer calories than normal, can lead to excessive eating and life-threatening obesity. At birth the infant typically has low birth weight for gestation, hypotonia, and difficulty sucking due to weak muscles (“failure to thrive”). The second stage (“thriving too well”, with onset between the ages of two and five throughout lifetime, may show increased appetite, weight control issues, and motor development delays along with behaviour problems. Other factors that may cause difficulties include negative reactions to medications, high pain tolerance, gastrointestinal and respiratory issues, lack of vomiting, and unstable temperature. Several medical complications can develop rapidly in individuals with PWS”..

Mommy has been researching endlessly and I am now on a special eating plan, receiving Growth Hormone injections everyday (in my bottom!) and seeing a speech therapist and physiotherapist weekly.

What has amazed the doctors and therapists is that despite the fact that most Prader-Willi Syndrome individuals have an average IQ of 70, I appear to be well able to hold my own in this area. (I could have told them this). My receptive language is good and I talk all the time. Other people find it hard to understand me as I have difficulty getting my consonants out but they will learn. The speech therapist is helping me to use the muscles in my face and mouth better. Mommy also keeps doing the baby gym exercises to help me.

Although I have Prader-Willi syndrome it is obvious to all my doctors and therapists that I have had a good start in life. The stimulation mommy and nana did with me in my early years have really helped me. Now all we need to do is continue to build on this to give me the best chance at a productive life that we can. I love to learn so this will help and of course mommy is determined I will be the exception to all the odds.

I thought you might like to use this to encourage other mummies with special children to always look for the positive and just make every effort to give their child the best they can. My daddy and mommy are determined to and I love them so much for it.

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