

Massi's Muscles

July 2014 was the month I was due to have my third and lucky last baby. Our family was a conventional family (2 adults and 2 kids), Myself (Anna), My husband Christian and our 2 beautiful boys, Luca 8 and Leon 6. We live in Sydney Australia.

We had tried for years to fall pregnant with number 3 and we were stoked when it finally happened. My pregnancy was normal and apart from my worry and concern, seemed fine to the midwives, sonographer and doctors. I kept telling myself not to worry but even expressed my concern to my close friends and family. I would say "I can't wait to get him out and see that he is ok" and the good old "its not the delivery that matters, its a healthy baby". I think it was about 37 weeks when I started feeling super concerned and cried my eyes out to a midwife who took notes and tried to reassure me that I'd had two healthy babies, there was no reason to feel worried. At 40 weeks it got to me so much that I called the hospital worried that my baby had stopped moving and they had me come in straight away. The next day I was induced and had an amazing 3 hour natural birth in a maternity hospital with the same midwives I had for my other boys...

It was to be the calm before the storm...

I saw my purple baby for about 15 seconds before the alarms rang and about ten nurses and doctors were in the room, they were breathing for him and (I found this out last week) when they left the room they were doing chest compressions on the way to the nursery. He was intubated while the ambulance was on the way and my baby and husband were off to a bigger hospital. I was a few hours behind.

Christian and I agreed on a name while he was in transit.



Massimo Edmund Mencio

Edmund is my late grandfather and I only ever remember him as "Ted"

Massimo "Ted" Mencio, initials, ***MTM*** ... crazy hey!

Massi was tested for all sorts of things which we didn't google or ask about in fear that we would find something we didn't want to know. At day three he was still extremely floppy, not sucking or swallowing and definitely not breathing on his own, in fact he was triggering zero breaths per minute. We learnt how to read the machines that were doing all the work for him. On a positive note, I was about to hold him for the first time.

He was just perfect!

Looking back, I feel as though we were treated very well because we had the baby that *wasn't going to make it* and (don't we all) I wish I knew as much as I do now.



In the following 14 days Massimo started 'waking up', bit by bit he started moving and following us with his eyes. We were excited to see the doctors at the rounds and fill them in on our findings. It was then that they decided to transfer us to The Children's Hospital at Westmead...



After a few days the doctors told us that they would try to turn down the ventilation and see if Massimo would trigger any of his own breaths. It was slow but he ended up doing really well and we decided to try take the tube out and see what happened. He was straight on CPAP after extubation and didn't de-sat over the next few days. He was able to have long periods off CPAP and, at four weeks of age, he had his FIRST bath... he loved it!

A week or so later and we were out of the ICU and into the HDU (high dependency unit) where he stayed until he was 7 weeks old.



Massi's Discharge

I had learnt so much about the care of Massimo already and took home a baby with no diagnosis, who needed roughly 4 nasal or oral suction each day, was on CPAP during sleep time only, was NG tube fed 6 times a day, and slept through the night. I could successfully insert an NG tube into the lung... as well as by pass the stomach and insert one into the small bowel... so when I got it in the right spot first try, it was a bonus... did I mention that my baby slept through the night!!



At three months of age we received news of the DNA muscle panel results, Massimo has **MTM** (X- Linked Myotubular Myopathy). I was devastated to find out how rare it was and desperately wanted to ask other parents questions that my neurologist couldn't answer. Not long after, good old google lead me to the wonderful Alison at the Joshua Frase Foundation and loads of supportive people! One of whom lives in Australia and has become my trusty 'go to' when I need answers, advice or just someone who understands. *(Thank you so much Michelle and George, you are forever our inspiration!)*

Massimo is now 13 months old and is perfect just the way he has come. Some of his other milestone have been sitting up in a hi back corner chair or hi chair for a few hours at a time which he started doing from about 10 months, making sound which he started doing at 11 months old, clapping and waving from 12 months and he has just started pushing himself forward in his new zipzac wheel chair. Massimo has been my happiest baby :)



Massi's Muscle Team

Massimo has been doing hydrotherapy, PT & OT, he has a Sleep team who have recently changed him to BiPAP, he has a Speech therapist, Dietitian, ENT team, Neuromuscular team, and wonderful Palliative care support.

I could not have gone through the past 13 months without my husband who has been my rock (and me his) when needed. This life changing baby boy has brought out so much love and support within our now family of 5. It has completely put life into perspective not only for us but for our close friends and family who now have an appreciation of life that's otherwise expected.

With Massimo, Luca and Leon in toe we will **fill their lives it to the brim** with **love**, **hope** and so so many **happy times**. However... to the day I die, I will be searching, supporting and striving in any way I can, to find a cure.

Anna xxx

