

Tahlia's Story



Tahlia was born on 25 May 2006 at North Shore Private Hospital in Sydney. Everything went well and a beautiful little sister for Matthew arrived. After about 12 hours though, Tahlia was taken off to the nursery because she wasn't feeding. That unfortunately was the start of a long journey!

Unbeknown to us at the time, Tahlia's blood sugar and body temperature had unexpectedly dropped very low. She was admitted to the special care nursery where she quickly started to pick up and improve. After a few extra days in hospital while they tried to control her jaundice we finally went home.

That unfortunately only lasted a few hours as it was obvious to us that not all was well. Tahlia ended up back in the Special Care Nursery that same day. Blood test after blood test followed to no avail as she continued to struggle with feeding (her poor little heels were like pin cushions). She was so quiet and hardly ever cried. But her paediatrician persevered and after about 3 weeks she was diagnosed with Congenital Hypopituitarism.

Once we were told, it was like our whole world had been turned upside down – daily medication, daily injections, what will the future hold? Looking back on it now though, as daunting as it felt at the time, it is all now part of life and we are blessed with a beautiful daughter who is now thriving and growing with a 'cheeky' personality and keeping up with her big brother!

The first few months were hectic and a bit of a blur with what seemed like one appointment after another – paediatricians, endocrinologists, ophthalmologists, MRI, ultrasounds, blood tests and to top it off at about 6 weeks old, we were told she had hip dysplasia and had to spend the next couple of months in a hip brace. We were amazed at how Tahlia adapted to it all though as we struggled with giving her daily tablets and injections. Whilst a very stressful time for us personally, it was made a lot easier with the love and support from our families.

Tahlia has been taking Thyroxin (Oroxine), Hydrocortisone (Hysone) and Growth Hormone (Humatrope) since the day after the doctors diagnosed her. We feel quite lucky that she was diagnosed so early and was able to commence the medication straight away. It's all a constant routine for us now and it makes it much easier now that Tahlia is able to chew the cortisone tablet. We think back to the very early days though - we had to crush and mix up the tablets with a little milk then squirt it into a teat and hope for the best that she wanted to suck right then!

One thing that stands out to us is the support that exists from other families in similar situations and organisations like the APF. We were put in touch with a few families of children with hypopituitarism and it was great to be able to talk to someone who has been through what we had just begun.

The Children's Hospital at Westmead was another valuable support which we discovered when Tahlia was about 3 months old. The Specialists and Nursing Educators put it all into perspective for us and taught us an easy way to give the tablets and provided information on how to manage emergencies and illnesses.

Tahlia's Nanna and Poppy care for her one day a week and she attends child care 2 days. Whilst sending her to childcare was a bit nerve racking to start, we continue to remind the staff about her condition and medication requirements to ensure everyone stays on top of it. While never complacent, we are confident to let her experience life like other children.

Our son Matthew, while only 5, has been a massive help and support throughout. Matthew loves his sister dearly and is very protective of her and sensitive to her condition. There have been times lately where it has been quite difficult to give Tahlia her injection without her kicking and screaming and we found Matthew would find ways to help distract her and make the 'situation' easier to deal with. In fact, one day he could see us struggling to give Tahlia her injection and happily announced he'll have one first to show her it's ok. So through gritted teeth he 'took one for the team' and had an empty injection in the thigh and still managed a brave smile – all this for his little sister! (*or the lolly bribe at the end*).



***Tahlia with her big brother Matthew
at North Shore Private Hospital***

Thankfully so far, Tahlia has stayed quite well and has had very few illnesses which have required anything more than some TLC and extra cortisone.

Tahlia has regular blood tests and sees her Paediatric Endocrinologist every 3 months at Westmead Children's Hospital to monitor her growth rate and adjust her medication levels to suit her growth.

It is wonderful to see her growing and developing well.

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