

## Elizabeth – Our Tiny Sweet Fairy



**Elizabeth as a 1 year old**

Our Daughter Elizabeth was born June 2005 at the Mater Mother's Hospital. At the beginning of my pregnancy all was fairly normal, apart from terrible heartburn. The doctors watched my progress very closely because of my age, which at that time was 38 and all tests returned—with good results. When I was 39 weeks my blood pressure was up slightly and stayed that way for the rest of my pregnancy. My hands and feet were swollen, which indicated that I had a mild case of pre-eclampsia. Due to my age and previous history, complete rest was advised. First at home, but when my blood pressure didn't settle properly as they had hoped, I was admitted to hospital to be induced. Three attempts were made to induce labour by use of a gel but all attempts failed. I was then sent home for a few days to rest and see what would happen naturally. At 41 weeks I was feeling extremely uncomfortable and things weren't progressing as hoped. so again I was admitted and this time they broke my waters. This was at 4pm in the afternoon, it took over two hours before labour actually started. Then another 6 hours before Elizabeth was born.



**Special care 5 days old**

She weighed 9pd 2oz, and *was* by no means a small baby. Elizabeth was very lethargic and didn't wish to feed straight away. She was very quiet in comparison to my other three children. The doctors were concerned, but felt her size and the difficult labour may have been the cause of this. A few hours later we were both resting in the ward, when one of the nurses arrived and said that they wished to check Elizabeth's Ob's. A heel prick was performed and her blood sugar levels were checked, which came up at 0.08. It was dangerously low, we were told. The nurse told me that she had to take Elizabeth across to special care for a few hours or maybe a day, to see if they could get her blood sugars to come up. They placed her on a glucose drip to help

her but she was still, very sleepy and didn't feed that well, so a nasal tube was inserted to make sure she was receiving enough milk at her feeds.

The glucose drip unfortunately wasn't having the desired affect, so they changed it to a glucagon drip which was ultimately able to maintain her blood sugars at an acceptable level. She remained in special care for just over a week in which time they tested for a bacterial infection and many other things, while there she also required treatment for Jaundice. The first idea of a diagnosis was hypothyroidism. Which neither myself nor my husband had heard of. Elizabeth was then transferred across to the children's hospital into a general ward under the care of the endocrine team. This was the first time we had the pleasure of meeting her Paediatric Endocrinologist.

He told us that they were going to give Elizabeth cortisol to see whether this made a difference to her and if so, then it would mean that she had a deficiency and could be diagnosed as having congenital Panhypopituitarism.

She responded well to the treatment set out for her, in a few days we were able to finally take her home. That was the best feeling of all. At one year old Elizabeth had a series of tests performed which showed that she was growth hormone deficient. A bone growth test was performed as well which showed her growth rate had dropped down to almost the lowest percentile and was now a few months behind other children of the same age. An MRI was also done which confirmed the diagnosis the doctors had made when she was 2 weeks old. She started on growth hormones at 14 months.



We have learnt a lot about Elizabeth's condition in the last three years. It was rough going at first. It took time to get use to having to give daily medications, then the injections, regular clinic visits, blood tests, keeping an eye on her wellness and learning the signs to know when to increase her medication and late night dashes to the hospital. One thing is true though we wouldn't swap our sweet bundle of joy for anything, through everything she still amazes my husband & I because even in the tough times when she's in hospital and feeling really unwell she still has a cheeky smile for everyone and a bright bubbly attitude. We are so grateful to all the doctors, nurses and staff of the Mater Mothers Hospital for all they did for Elizabeth and us. We have also found it really great to be able to meet other parents and children in the same situation as ourselves.

#### Latest Update:

The story of our Little Fairy Elizabeth continues, though she is not little anymore. Elizabeth has grown so much since the story of her birth and diagnosis, in all ways she is like any other young girl getting ready for her 8<sup>th</sup> birthday. I can't say things have always been easy in the past few years but we have all learned to adapt and do what must be done to make sure Elizabeth is always healthy and achieves all she

wants to achieve. By the time she was 3 we had made many trips to the hospital and had at least 4 stay overs. Drips and extra medication and people doing observations around the clock and also being in an isolated room are not what most would call fun. Elizabeth still always had a smile for all the staff and seemed to make the best of the situation. Elizabeth loves school; her first day at prep was the happiest day in her life so far. We consider ourselves fortunate to have found a really supportive doctor and school. I was uncertain how things would go with having to have an emergency needle with her at all times while at school and extra tablets but after working together with school staff we have a great routine that suits us all now. Our routine at home to date is 6 monthly blood tests, 3 monthly clinic visits, daily tablets and evening needles. She has developed some interesting sayings and a few clever ways to explain her medical alert bracelet to other kids. There have been tears and tantrums and questions about why don't other kids have to do all this stuff. Meeting other children like her has been a big help with this. Other times we just do what most parents have to and get her to see in her own way that it's the best thing for her. Once she was old enough to understand we started a really good reward system which has also been a big help in awkward situations. We are proud to say Elizabeth now sits for blood tests on her own even though she still hates them; she swallows tablets and reminds me that her needle at night is due. The journey so far has been far from easy but we have learnt a lot and are still learning and I can say that I feel blessed to have a wonderful young lady in my life that has taught all of us that when life hands you lemons make lemonade.

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