



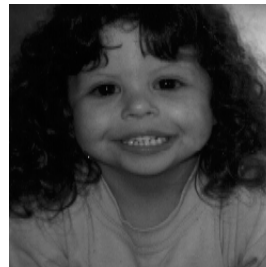
Phoebe's Story

I'm sure most of us, at least once in our lives, have seen a butterfly, and whether it's colourful or just white, big or small, have thought, "Wow, look at that butterfly." For the few seconds that we stop and marvel at its prettiness and watch it flutter away we are left with a feeling of having witnessed something really special. I have three children, Alexandra nearly 10, Phoebe, seven, and Isaac, now three and a half. They are amazing people and every morning I wake with such a feeling of wonder and gratitude that these little beings are in my care. The three of them are very special with their own incredible attributes, but it is Phoebe, who is my little butterfly. When you meet Phoebe you are left with a feeling of having witnessed someone really special! My husband Hani and I were over the moon when our daughter Alexandra came into our lives in 1993. There was no question that we wanted another baby, and were thrilled with the news of our second pregnancy, however this happiness was short lived when I miscarried at around three months. The very next month we were dumbfounded to learn that I was pregnant again, but unfortunately this pregnancy was not to be an altogether smooth journey either. At a routine blood test I was told that I was in a "high risk category" for Downs Syndrome and was advised to have an amniocentesis test. After waiting for six weeks the results came back that everything was normal and no Downs Syndrome was evident. We then lived through a relatively easy pregnancy until at 41 weeks and six hours of labour later, our tiny little Phoebe Kate was born.

The day of Phoebe's birth was one of complete elation and exhaustion, and the start of a relentless, nagging feeling that not all was right with our new baby. Phoebe had a low birth weight of 2430grams (5lb 5oz), and the obstetrician noted that the placenta was quite gritty and had started breaking down. Because of this a paediatrician was called and discovered that Phoebe had a heart murmur. Further testing with the cardiologist confirmed that Phoebe had two pulmonary stenosis, Aortic stenosis, two holes & what was described as a "trickle back" with every pump of her heart. Phoebe also had hyperglycaemia, which settled at around day five, so we were able to take our very unsettled new little girl home. The next few months were a blur, at the time, but I can remember them quite vividly now. Phoebe **never** slept, and if she did, it was for no more than 20 minutes at a time and only if we held her. We had visits to the paediatrician and check ups at the cardio, and when we mentioned how unsettled she was we felt as if we were passed off and told that she was doing well. So we would go home and try everything to get Phoebe to sleep, but nothing prevailed. Hani would often come home from work to find Alexandra and I still in our pyjamas, no dinner prepared and the nappy bucket emptied into the washing machine, but not yet washed. All I had done all day was try to comfort my crying baby.

It was very different to what I was like as a first time Mum. I would have a 'panic attack' if the nappies weren't on the line by 8:30am! I don't know how Hani coped then either. He would nurse Phoebe through the night so I could get a couple of hours sleep between feeds, then he would try to get a bit of sleep himself before getting up for work. We were both so stressed & worried. We were then living in a tri-level terrace house in Rockdale and knew that it was a very impractical home for children, so we decided to build in Glen Alpine. We now know that we were meant to move to the Macarthur region. If we hadn't who knows how long we would have been wondering what was wrong with Phoebe. When we moved Phoebe was about 10 months, still screaming, mainly at night (just to make life that little bit easier to cope with!) and was not reaching any normal milestones. She suffered from terrible reflux and vomiting all the time. With Phoebe's heart condition we needed to find a paediatrician in the area.

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On our first meeting with local paediatrician, Dr Rick Dunstan, he said that although he didn't want to alarm us, he could see there was something wrong with our little girl. After months of heart checkups and blood tests, we finally got in to see geneticist, Dr Alison Colley. She knew immediately what Phoebe had and why she was restless, failed to reach milestones, looked so different to her sister, had trouble feeding, and vomited all the time! At 18 months of age, Phoebe was diagnosed with Williams Syndrome. We were devastated. I was also saddened by the fact that Phoebe would never be able to have children. We spent many nights crying ourselves to sleep, wondering what was to become of our beautiful little girl.

We contacted the Williams Syndrome Association and were invited to join them at the annual Williams Syndrome picnic day, held at Mater Dei. This was just three weeks after Phoebe's diagnosis, so we were fortunate to meet other Williams children and adults and their families. But it was really difficult and I cried all the way home. We also got in touch with Families First Macarthur, (now Starting Points Macarthur) a support group for families of children with disabilities who became our family for the next four years. Phoebe also went to the Stepping Stones program - an early intervention preschool and I helped out on a voluntary basis. This support group helped us so much. We learned a great deal from the parents and the wonderful staff. It was through this support that we learned how to be advocates for our daughter and also how to reevaluate our expectations for her and 'grieve' the loss of those expectations. Phoebe received physiotherapy and occupational therapy through Campbelltown Early Education Programs and had private Speech Therapy. We were well and truly on the therapy merry-go-round, which I was assured would stop once she went to school.

Towards the end of 1998, Hani suggested that we should have another baby. At first I was totally against the idea especially after seeing other families with more than one disabled child. But I soon realised that another child in our family would only provide a more supportive environment for both Alexandra and Phoebe, and before too long I was pregnant. This time I didn't want to have any testing, except for the usual 16 week blood test which again came back in the high risk category. I never fully relaxed during this pregnancy but both Hani and I were relieved when our son, Isaac, was born healthy and well.

The subject of Phoebe's schooling was daunting. At first, we thought that she might be able to attend the same school as Alexandra because they had a learning centre for intellectually disabled children, but unfortunately, circumstances did not allow our girls to go to school together. Phoebe now attends Mater Dei School and could not be happier. After attending the School Staters program last year Phoebe is now in Year 1 and just loves it. We are so fortunate to be a part of this beautiful school and its warm, welcoming community. Mater Dei has made the transition from early intervention to "big" school not quite as daunting as we first expected. The level of care and learning Phoebe is receiving is exceptional. Her academic needs have been recognised and addressed through her individual program and this term Phoebe is commencing her inclusive schooling at Our Lady Help of Christians, Rosemeadow. This rather large step in her school life is being taken one morning a week to begin with. Phoebe's enthusiasm towards this endeavour is very encouraging.

To attend a function at Mater Dei always leaves me with a sense of gratitude that Phoebe is part of such a wonderful school. The reverence of the students at a Mass or Liturgy is lovely and to see the pride and happiness of the students at a sporting event is uplifting. The respect of the Mater Dei staff for the students and the support given to families is also heartening. Phoebe is learning the true meaning of school spirit and pride by being a student of Mater Dei School. As far as our aspirations for her future, well it is hard to imagine. We know that the gap between Phoebe and what is considered “normal” will get bigger as time goes on and we can never really see her living independently of us. Funnily, we were talking recently about the countries we would travel to in our retirement and Phoebe, whom we thought was watching television, turned around and said, “Yeah, just me, you and Dad, hey Mum?” Eventually we would love to build a home with a granny flat for Phoebe so she can have some independence, but it is hard to imagine her future when she still can’t write her own name (although that is definitely coming along).

Life with a disabled child has changed us. We are no longer the same people we were six years ago. We have our ups and downs like everybody. At times, it’s heart wrenching to watch Phoebe trying to grasp something that comes naturally to other children, or to keep up with other kids, but she amazes me with her compassion and love and delights in her sister’s and brother’s achievements. We have learned so very much and still have much to learn but we are very grateful that this one child, this beautiful little girl with her mop of curls and cheesy grin, and ‘oh! so’ tight hugs has changed us forever. We gain inspiration from Phoebe and knowledge from other parents and from those who work with Phoebe. We are determined to fill Phoebe’s life with happiness, love, dreams and memories to treasure. It’s only fair we give this to her. It’s what she has given to us!

Donna

Phoebe’s mum



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