

Our Beautiful Daughter and HeartKid Bella

Bella came 6 weeks earlier than expected. Glen and I were so happy to finally meet our little Girl.



At 5 days old, the Doctors were wondering why she wasn't improving and wasn't "acting" like a 5 day old preemie. That was when we met Dr. Andrew Bullock for the first time. He told us Bella had Congenital Heart Disease, a rare heart defect called "Truncus Arteriosus", she also had Ventricular Septal Defects (VSDs).

What did all this mean?

We quickly learnt that this was very serious and she would require open heart surgery and the odds of her surviving the surgery at 4.5lbs (1.9kg) was not encouraging. If she did survive she would also require subsequent surgeries as she grew - for rest of her life!

To say we struggled with the news, was an understatement. We were devastated! How could our perfect little baby be so

sick and why hadn't this been picked up during antenatal ultrasounds???

We immediately contacted our parents and had a late night get together to break the news. Everyone was shocked and stunned!

Bella was moved that night from King Edward Memorial Hospital to the NICU at PMH. We saw her the next morning and tried to come to grips with what was facing all of us. I felt numb, all I could do was cry and pray.

We spoke with Dr. Bullock again and the decision was made to send Bella to Royal Children's Hospital in Melbourne. She would have a better chance if she was bigger, but if we waited for her to put weight on, she would be too sick to have the surgery...



We contacted immediate family and they came in one by one to say their goodbyes to Bella. We both decided that Bella's Half-Brother James (6.5 y.o.), would not see Bella. We struggled to make that decision, but felt if she didn't survive the surgery, it would be easier on James if he had only seen photos. Also we were worried that seeing her, the way she was,

would upset him more, than not seeing her. It was a very hard decision.

Five days later Bella flew with RFDS to Melbourne for complex open heart surgery to save her life. We met her there that night.



The next morning the Doctors took her into theatre, we said goodbye to our beautiful little Girl...it felt so final! What if this was the last time I saw her alive – it was SO overwhelming.

Late afternoon the phone finally rang. I couldn't answer it – what if it was bad news? Glen took the call...

Thank God! Our little Bella had beaten all the odds and made it through 10 hours of surgery!

We couldn't wait to see her. The lovely Nurse we met, tried to prepare us for what Bella would look like, but NOTHING could have prepared us for what we saw! She was so sunken in the face, she looked like a different baby – so fragile. Then I looked at her chest – it was still open, it was only covered by a clear bandage and the some fine gauze. I could actually see

movement in there – it was horrifying! Glen and I held each other – there was silence.

For the next 3 days we watched Bella fight to stay with us. Every day we would ask if they could close her chest. That decision had to be taken one day at a time. Her heart was so swollen from surgery and because she was so small they couldn't risk closing her chest until the swelling had improved or this could put pressure on her little heart. But the longer it stayed open, the higher risk of infection. We felt totally helpless, all we could do was watch and pray. After 4 days, the decision was made to close her chest, with the warning that it may have to be reopened if her heart doesn't recover well. Her heart remained stable.



A week later she was well enough to leave the ICU and move to the Cardiac Ward. There we watched her slowly recover, we were able to hold her, bath her and try breastfeeding. The first time I held her, I didn't want to let go, we cuddled for 2 hours! I believed then and still believe now that a Mother or Father's touch is so comforting and healing. Her stats would

actually improve while being held. Glen and I held her as much as we could!

9 days after that, we were all on our way back to Perth, to PMH.

FINALLY - after waiting 4 weeks - James met his little sister for the first time! It was a beautiful sight, I'll never forget it!



2 weeks later, we finally took our Beautiful Bella home!

The next 6 months were wonderful! Life got back to normal and we all adjusted to having a newborn at home. Bella fitted into her routine easily and did a great job at growing. She tripled her weight! We were relieved that she was doing so well.



That wonderful feeling stopped when Doctors told us she would now require another open heart surgery, this time it could be done at PMH by Surgeon, Mr. David Andrews.

Once again our lives were turned upside down. We prayed Bella would get through another big surgery.



The surgery went very well. She amazed us over and over again. Bella spent 8 days at PMH recovering. Then, once again, life went back to normal.

2 months later it was discovered that Bella's nerve that holds her diaphragm had been injured during her last surgery. In turn the nerve had shrunk and lifted her diaphragm into her left lung – her lung was 25% collapsed. Because it had only been 2 months since surgery, it was not advisable to operate. She would be monitored and the surgery would take place in a few months.

2 months after that, it was decided that Bella would require another open heart surgery to expand her pulmonary arteries. The arteries were not growing fast enough

(this is not unusual in patients with Truncus Arteriosus) and were restricting blood flow to her lungs. Considering she already had a collapsed lung, it made the situation more urgent. We were so worried - how could she recover from another major surgery this soon!

This time Bella's surgery did not go smoothly, she was about to be moved to the ICU and she started to bleed. Her chest had to be reopened to stop the bleeding. I couldn't breathe - it was an hour before we were told it was under control. That hour was the longest hour of our lives, we didn't know if she was OK or not! But Bella amazed us yet again – she fought through it all and spent 10 days in hospital recovering.



During her stay in ICU, Bella turned 1. Instead of planning a wonderful big party at home, like most parents do, we celebrated with close family in ICU. The wonderful nurses in ICU decorated Bella's bed and face, brought presents and we all sang Happy Birthday.



4 months later, Bella was finding it hard to fight off a head cold and was admitted to PMH with decreased oxygen levels. This then turned to Pneumonia and she was moved to ICU. Bella spent 2 weeks fighting it. It was discovered during this time that her left lung had totally collapsed.

The decision was made to operate on her diaphragm and to move it out of her lung and in turn reinflate her lung. At the same time a stent was put in a narrow section of her right pulmonary artery. The operation went very well and Bella improved almost straight away.

When we saw her in ICU we were stunned, Bella was a beautiful pink colour instead of the bluish-grey colour we had grown accustomed to. She was never able to get her oxygen stats higher than 80%, we were stunned when the monitor showed 93%.



and support helped more than she will ever know!

Also a very big thank you to Kelly, Julie, Andrew, Steve and the wonderful Cardiology Team at PMH, your skill, commitment and dedication is amazing!

Lastly and by no means least - without David Andrews and his magic hands, Bella would not be here with us - we can never thank you enough David!

Written by Michelle McHarg

Bella spent a month (this time) at PMH recovering. It has all been worth it, we now have a very energetic 18 month old toddler, who isn't crawling yet, but is certainly on her way. She is now putting on weight for the first time in 10 months! Glen and I couldn't be happier!

The last 18 months have taught us to take each day as it comes, celebrate every milestone (no matter how small) and be grateful for what we have – a beautiful little Girl who really wants to be here!

We now understand that Bella's condition needs constant monitoring and tweaking and her future will include lots of visits to PMH.

We are lucky to have such wonderful family to help and support us and when they can't be there, the lovely people from Heartkids are! We want to thank Maree Green in particular, whose visits