

2 HOSPITALS.
50 DAYS. 1200
HOURS. 10
DIFFERENT
SPECIALISTS.

Xanders Journey.
Raising awareness for Childhood
Heart Defects/Disease.



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Our journey began early, as excited expectant parents looking forward to the birth of their child, our world came to a standstill when we went for our 20 week scan, and were told that our child's heart had not formed properly.

Two days later, we saw our first specialist, a paediatric cardiologist and everything was explained in more detail. However the 'we won't know until..' was our biggest anxiety and biggest challenge.

The day Xander was born, he was whisked away from us and taken straight to the Neonatal Intensive Care unit at Monash Hospital, where we spent the next 22 days. Leaving the hospital after giving birth without our son was the hardest thing I have ever done at that point.





Xander was the happiest baby, given all he had going on and all he's gone through, he was still nicknamed 'Mr Smiley'. He was strong and resilient and wanted to thrive. He just needed extra help and the amazing staff at the Monash allowed him to do that and he came home after 22 days in hospital.

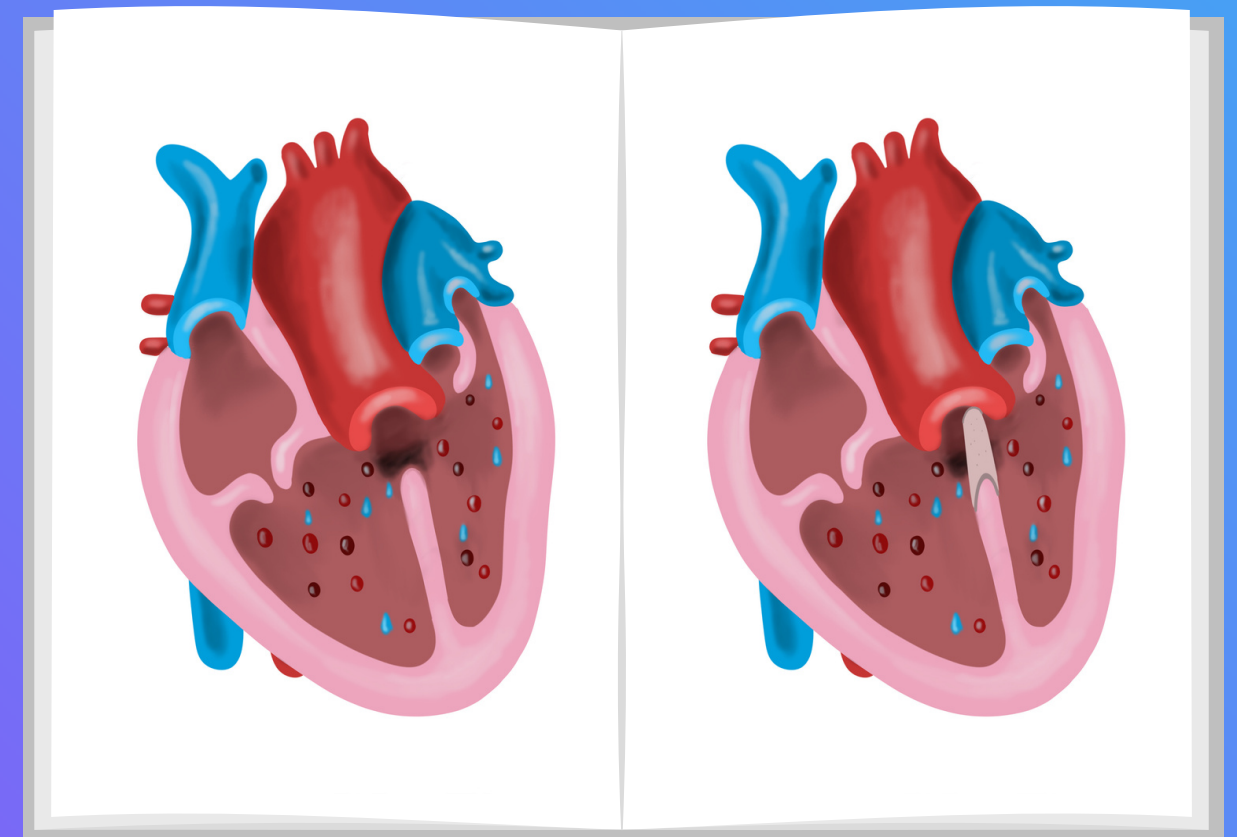


Next came the worst waiting game. For the next 6 months, we had to wait for Xander's condition to deteriorate to the point that he 'had' to get surgery to repair his heart. We sacrificed many things as a family to keep him healthy and as well as we could until that point of no return, the 'it's now or never' moment of him needing surgery.



Xander underwent open heart surgery to repair his heart defect, which is called Tetralogy of Fallot. His aorta is overriding (in the wrong position), His pulmonary artery was too narrow and needed to be widened, the dividing wall that should separate the two lower chambers was missing a large portion and needed to be patched, and finally, because his heart had to work several times harder, the muscle around his heart will always be thick.

The surgery took 7 hours, and it was the longest 7 hours of our lives. We tried our best to distract ourselves but the enormity of the situation and the fear of 'will we see our son again' was in the forefront of our minds.



Pre- Surgery

Post-Surgery

Xander made it through the surgery and it was a success, however we spent another 18 days in hospital. He had complications that resulted in a collapsed lung, he was in extraordinary pain and would scream for hours. The first night nobody slept and all we could do was hold his hands and stroke his head. His drains failed, he went through withdrawals, he had to be fed through a tube. It was horrendous time of post surgery and recovery.

We all survived through the love and support of our community who brought us meals, sent cards, texted, and even helped pay for our hotel room so we could be close to Xander.



During our stay at the Children's Hospital, we realised that we were the lucky ones. That despite our hardship, we had our child with us, and his heart was fixable. We are so grateful for the amazing medical advancements we have here in Australia. If Xander was born anywhere else, his chances of survival would drop by 50%. Still with all the medical advancements, 4 children pass away each week in Australia from CHD and 8 Children are born every week with some form of CHD. There is no cure, there is no prevention. All we all can do is help others, and be grateful for our health. That we can gather to play a game we love Basketball, that despite an outcome of the game, we are winning because we can play.

Xander will have every opportunity ahead of him in life because we have such a wonderful local community full of amazing health professionals and people who care.