

Thea's Story

It was quite a shock when Thea Louise Barry eventually entered our world late on a Saturday night in February 2001. But not for the usual reasons. I had an easy pregnancy, labour and birth. I vaguely remember holding her for a split second before she was whisked to the Neonatal Unit. A nurse assured us it was just for the night. But I could see the looks on my husband, David, and my Mum's faces ... I woke early the next morning to find I'd been put in a ward with two other babyless mothers. Their babies were premature; no one seemed to know what was wrong with ours. David was already at the hospital. We were told our baby was being treated for a lung problem and wasn't breathing well. She needed specialist help.

The hospital staff began calling major London hospitals for an intensive care bed. It seemed like hours of waiting around whilst our babe lay in that tiny incubator in a unit that couldn't cope with her condition. She looked enormous compared to all the other babies on the unit. At 6lbs 6ozs she was big next to the one and two pound prems. Then the Sister came with more news. The doctors had been talking to Guy's and St Thomas' Hospital and they confirmed a heart condition, not a lung problem! They had immediately switched treatment and were being guided by the doctors at Guy's. We just had to wait until a bed became available.

Guy's 'Ghostbusters' Come for Us

A bed wasn't available! We immediately asked to go private; we'd pay anything to get the help our baby needed. But we were quickly told that this kind of treatment was not available privately and a bed would be made available as soon as possible. Two hours later Guy's had vacated a paediatric intensive care bed and an ambulance was on its way. I couldn't understand why they didn't just use one of the ambulances sitting outside and didn't have the energy to ask (I later discovered the 'Ghostbusters' - teams of paramedics from Guy's carrying the entire cardiac units on their backs. They really do resemble The Ghostbusters!).

The paediatric cardiac team and ambulance and blue lighted our baby back to Guy's. We tried to follow but lost the ambulance on the packed South London streets. It was Sunday, where was all this traffic coming from? We then managed to get lost (two many relatives in the cars giving directions!). A friend, and London cabbie, giving street-by-street directions over a mobile phone, relieved the stress.

When we eventually arrived at the hospital our babe was already settled into the Paediatric Intensive Care Unit {PICU}. We were taken to a parent's room and told the full extent of her condition, transposition of the great arteries. Her aorta and pulmonary arteries had developed on the wrong sides of her heart. Her blood was not flowing around her body picking up oxygen and dropping off but flowing in two disconnected circles and circulating little oxygen. Her blood saturation levels were just 40% - it should be 100%. This meant open-heart surgery as soon as she was stable. The shock was unexplainable.



Thea with her Great Uncle Danny in Australia

I still hadn't taken this in when we were asked to sign consent forms for the first procedure to stabilise her. The doctor explained there is a 93% success rate on this procedure, high but what about that 7%? We didn't consider it for more than a split second, they knew what was best. I didn't really understand any of what was said apart from: 'terminal unless operated on in the first two weeks of life'. No sooner had we signed and sat down in the parents room on Russell Brock, another doctor was in front of us again. She was through the first stage and ready to see us.

PICU was a gleaming white, busy unit with just four babies' beds and buzzing machines everywhere. Those machines became our lifelines over the next 10 days. The staff was so friendly and reassuring. Our baby had her own dedicated cardiac nurse watching over her 24/7, with doctors and sisters at hand as well. We were asked to name her even though we hadn't really decide on the name, So Thea she

became and up her name went on her little white board above her bed.

Alone at last, well almost...

As we settled into this unknown situation in an unfamiliar place, our family members had gone unable to be any help and aware they were in the way, it became strangely quiet. It was just David, me and Thea for the first time.

We were offered a bed on a side ward of the Maternity Unit at Guy's. At the time we were just grateful to be on site and not to have to travel back to Surrey. But after two nights of listening to healthy babies (and my husband) crying in their sleep, I could take no more. It was a generous offer but I couldn't face walking past all those new Mum's cuddling, feeding and changing their babies. I would scurry past and run to, the now familiar, PICU. We decided to book into a hotel.

A date had been arranged for Thea's operation. We were introduced to Conal Austin, her surgeon. He explained what was to happen, when and how long it should take. All I remember is a tall, softly spoken man with enormous hands. How was he going to operate on my baby's heart with hands that size?! Thea had a date booked so we were now entitled to a room at Ronald McDonald House (RMH). No hotel for us, we were packed off to the Elephant Room at RMH. What a haven in the city. Quiet, friendly, clean and a direct phone line to the hospital in our room. We got our first night's sleep in days.

I spent most of these days expressing and bottling milk for Thea, sitting with her and David and chatting/joking with the nurses. They had renamed me Daisy because of my milk producing abilities. Thea was taking 2ml per feed and I had my own freezer reserved on Caleb for all the extra bottles! A new form of stress relief?!

Where do you go when your baby is having heart surgery?

At five days old Theo was stable enough to undergo surgery. When it came to the morning of the operation David and I didn't know what to do or where to go. Six hours to kill... not wanting to go anywhere but sit here and wait. Thea's nurse, Aussie Dave, suggested a walk on the Thames and a good pub. So off we went like two zombies. The quietest day out in a pub I've ever had!

Six hours, six units of blood, two units of platelets later and Thea was back on the unit. We stayed with her most of the night, she hardly moved. She looked so different and so small. A few days after heart surgery her lungs collapsed. This really hit me. It was unexpected, unplanned ... she was supposed to get better. The respirator was back on for days. Thea's body had reacted to the surgery on a major organ and another organ had been 'insulted'. But she recovered well and with a few highs and even more lows, was moved to Rothschild cardiac ward within five days of the operation. The visitors started flowing and Thea got stronger. She was well enough to be transferred to a local hospital to establish feeding. We went home within a month of her birth!

Health and happy...

Theo is now a very healthy four year old. Full of energy, fun and blood saturation levels of 97% - very good for a heart child. Outpatient check ups have gone from monthly to once every two years. Thea may never need another operation. This is all thanks to Conol Austin and his team at Guy's. How do you even start to thank them?

We have since had another child, Jake. We were told the chances of another heart baby double even though it's not hereditary. Distressing but that's still less than 2% chance. After many scans at Guy's we were given the all clear and in September 2003 along came a very healthy Jake at 9lb.

We're immigrating to Australia soon and would like to thank the ongoing support we have had from the team at Guy's and Dr Shakeel Qureshi.

But also thank you to Echo for all the support over the past four years. We've had great fun at your parties and events and made some life long friendships, no matter where we live in the world.