From: [redacted]
[redacted] Reproductive, Maternal and Paediatric
Subject: [redacted] Birth Story/Experience of Maternity and Paediatric Services
Date: Tuesday, 17 September 2024 8:26:52 AM

[redacted]

Good afternoon,

At my 20 week ultrasound only the right kidney could be seen so another scan was arranged for 24 weeks. The 24 week scan could also only pick up the right kidney so arrangements were made for a more detailed scan in Hobart when I was 28 and 32 weeks pregnant. I attended the Wellington Clinic and saw two different obstetricians. At 28 weeks, the obstetrician confirmed my baby did not have a kidney on the left and a large kidney on the right. I saw a paediatrician who discussed the possible implications of the baby having one kidney and told me the only way we would know the baby's true health situation is once he was born. He confirmed the baby would be probably be born healthy but scans and tests would be needed within 24-48 hours of being born as he could deteriorate if kidney function was compromised. At my 32 week appointment, the obstetrician told me she had spoken to a paediatric surgeon who said the baby should be born in Hobart. She advised I would need to relocate to Hobart when 37-38 weeks pregnant so I could give birth at the Royal Hobart Hospital and the baby would receive the care he needed. She said if I didn't go into labour naturally before 39 weeks, I would be induced. I thought there was a clear plan that the baby would need a blood test within 24 hours of being born, an ultrasound within 24-48 hours of him being born and a dye scan/test with nuclear medicine. I followed advice and relocated to Hobart at 38 weeks and gave birth at 38+2.

This is where the nightmare began.

Once [redacted] was born, I asked when blood tests and scans were scheduled but no one knew. I asked several times and explained my concerns that the plan wasn't being followed but no one listened and I was told it was fine to leave the tests.

As a first time mum I didn't know his urine stream wasn't normal, I didn't know how many wet nappies he should have. I expressed as much breastmilk as I could but he needed topping up with formula as well. [redacted] lost too much weight so we needed to stay until day 4. He had his first blood test before discharge.

On day 4, we went back to Ronald McDonald House to find them doing renovations and they didn't want us there between 7.30am -3.30pm. Considering we were away from home and I was trying to express breastmilk and needed bottle making facilities, it was too stressful and when they were painting outside our room, we were worried about paint fumes. We decided to move to a hotel with a kitchenette.

On day 5 we were booked in for an ultrasound and follow up phone consultation. We received a call to say we were free to go home. Five minutes later we received another phone call to say we couldn't go home and needed to stay as [redacted] had high potassium and creatinine levels, an obstruction in his bladder and required another blood test and more scans. We were advised to monitor for any changes, phone NICU if we have any concerns and go straight to emergency.

Day 6 [redacted] had the second blood test and his tongue tie was cut and he latched for the first time - didn't feed though and we left. That night [redacted] was really unsettled but we assumed it was because he'd had a big day.

Day 7 [redacted] was even more unsettled, he wasn't feeding, wasn't pooing, was very lethargic and constantly sleeping, so I called NICU and was advised to go straight to emergency. [redacted] was examined and admitted to the children's ward. [redacted] was required to undergo a PCR and RAT test at 7 days old, we were told if we chose for him to not receive the RAT test we were advised his care would be limited even though RAT tests are not recommended for children under 2 years old. Another blood test confirmed [redacted] had a urine infection and IV antibiotics were started. We were told the staph infection in his bladder and bloodstream was caused by the backflow of urine into the kidneys. [redacted] posterior urethral valve caused sepsis and then staph. Paediatric surgeons came and saw us to discuss [redacted] kidney and explained the surgery he would require (at that stage [redacted] was diagnosed with having a duplex kidney and we were advised he would need to have his bladder operated on, one of his ureters connected into his kidney as it should but the other didn't so his bladder wasn't draining as it should. For 12 months his ureter would drain directly into his nappy externally and when he's 12 months old another surgery would connect the ureter to his bladder internally).

Day 8, [redacted] had another ultrasound and scan with nuclear medicine, a catheter inserted and a lumbar puncture test. These tests showed [redacted] does have 2 kidneys but they are fused together on his right side. The obstruction in his bladder was from the valve that releases urine, not the ureters like first thought. The official diagnosis - crossed fused renal ectopia and posterior urethral valves.

On day 9 a meeting was conducted by [redacted] which included the surgical team, social worker, a paediatric nurse, myself, Jye (partner) and my mum, where it was discussed [redacted] would require a further 10-14 days of antibiotics, potential long term health issues, risks of procedures etc.

Day 13, a nasal gastric feeding tube was inserted as he wasn't feeding properly. In my opinion [redacted] was feeding fine, the issue was how slow the nurses would respond with getting bottles to us to feed him. [redacted] would be left waiting 10-20 minutes for bottles and by that point had gotten so worked up, he would exhaust himself and then be too tired to feed. This is not a reflection on nurses, it's an indication of a broken system where nurses have too much to do and can't meet basic needs or patients.

Both surgical doctors and medical doctors confirmed they knew nothing about the plan for [redacted] until he presented to emergency 4/5/[redacted] They had no records from high risk antenatal appointments as nothing was passed on. [redacted] did not receive the care he required at birth and became sick unnecessarily. Had the plan been put in place that had been discussed during my pregnancy and [redacted] received the monitoring and care he needed, this nightmare could have been avoided, his infection either wouldn't have existed or it would have been controlled very quickly.

Day 16, we are told [redacted] would require 18 days of antibiotics instead of 14 days as per directed by the Royal Children's Hospital renal team.

Day 21, [redacted] piic line stopped working at 12:30am, he was due for antibiotics at 9am. There was a delay until 4.30pm as a doctor wasn't available to put a new one in. We were asking for another piic so he wasn't in pain when he received his medication but in the end he had another cannula inserted so he could continue with the antibiotics. We were very frustrated as he was in hospital for IV antibiotics but for 24 hours he missed out. His 10:30pm dose was missed as the nurse on thought they weren't due until 12:30am. Had I not spoken up, his antibiotics would have been missed yet again.

I have a history of anxiety and depression and my mother was very concerned for my mental health and asked for support from Perinatal Mental health on 10/5/[redacted] The following week when she visited Hobart, she followed up again to ask about the supports for my well being but contact wasn't made until 16/5/[redacted] I had a face to face appointment with [redacted] 17/5/[redacted] however I feel like she only saw me to tick a box – she didn't provide assistance with coping strategies etc like I asked for. I found the time to be incredibly difficult, a roller coaster of emotions, exacerbated by the knowledge that the situation was caused by hospital negligence.

There were some amazing and dedicated nurses and doctors involved in the care of [redacted] however they were overshadowed by -

A midwife decided [redacted] should breastfeed and forced him to latch until [redacted] was screaming and I was in tears. [redacted] couldn't move his tongue past his gum so there was no way he could latch properly, drinking a bottle was difficult enough for him. She

wouldn't listen when I explained.
The weekend on call surgeon came in to tell us [redacted] would need dialysis and he was near the end of his life if he didn't improve. This messaging was completely different to Dr [redacted] and Dr [redacted] advice and extremely distressing to us.
Some nurses couldn't complete basic tasks with [redacted] couldn't work the IV machines and admitted to not working with babies before. It's very clear the hospital is short staffed but [redacted] shouldn't have to suffer because of it. My partner and I had to regularly remind nurses when medications were due. My partner explained to some nursing staff how to work the IV machine.
Frequent requests to make [redacted] bottles ourselves as we were capable and competent do so were finally listened to and [redacted] weight and wet nappies increased and the burden on nurses was less.
The financial burden resulting from the extended hospital stay also caused distress. Out of pocket expenses such as accommodation at Travelodge due to Ronald McDonald House undergoing renovations, car parking at Argyle Street carpark, loss of wages due to the extended stay and food.
We thank the doctors and nursing staff who assisted [redacted] and can now report [redacted] is being monitored regularly and is well and healthy. We do want there to be an investigation into the systems and processes that let our son down and almost cost him his life. We don't want another family to go through what we did.

I have also attached the letter of response.

Regards,

[redacted]