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The Secretary
Select Committee on Reproductive, Maternal and Paediatric health services in Tasmania
Parliament of Tasmania
Parliament House
HOBART TAS 7000

Dear Secretary

Re: Submission to Select Committee

Please see below our submission regarding our experience relating to the premature birth of our son [redacted] on [redacted] at Royal Hobart Hospital and related medical care:

1. My wife became pregnant in mid-[redacted] Her first trimester was marred by chronic morning-sickness and nausea, loss of appetite, loss of sleep, and loss of weight. During the second trimester she developed gestational diabetes, and towards the end of the second trimester rising blood pressure which developed into preeclampsia, as well as severe cholestasis of pregnancy. These conditions were treated with a variety of medications but resulted in my wife becoming very unwell towards the 28th and 29th weeks of her pregnancy.

2. She was admitted first admitted to hospital on [redacted] and remained there until 28 December [redacted] when she self-discharged early.

3. On [redacted] at or about 11:15am I was contacted by my wife's obstetrician advising that the state of her health (and the consequent impact to the health of our child) now required our child to be born by emergency caesarean. He advised me to attend Hobart Private Hospital forthwith.

4. My wife was transferred from Hobart Private to Royal Hobart Hospital at or around 1:30pm. When we were waiting in the preparation room for surgery, nursing staff advised that Hobart Private had not sent her paperwork. The nursing staff then began to argue amongst themselves about who would go and get the paperwork. The nurses continued to argue for several minutes. They admitted to us that information transfer and communication between RHH and HPH was poor and that the non-transmission of patient paperwork was common.

5. In relation to the argument between the nurses, I noted a distinct lack of leadership, initiative, and professionalism demonstrated by the staff involved. In fact, given all emergency obstetric surgical deliveries are undertaken at Royal Hobart Hospital I find it simply galling that clear policies aren't in place between Hobart Private and Royal Hobart for transfer of files.

6. This was further exemplified by the attempts at administering intravenous medication to my wife in preparation for her surgery. She had a magnesium solution being administered to her left arm (her good arm) to prepare our child for being born prematurely, and so it was necessary to use the other arm to administer other medication. It took at least 15 attempts with multiple nursing and hospital staff to successfully insert the needle. My wife has previously been terrified of needles, so to witness this, in addition to the disregard and inappropriate humour expressed by some of the staff over their lack of success did not help the situation.

7. It is important to note that for both my wife and me, our experience of the obstetric and surgery team led by Dr [redacted] was brilliant. The birth itself, was successful, and my wife's care with the staff in the surgery was outstanding. She recalls feeling much calmer during the actual surgery, that staff listened to her and made the effort to provide her with comfort and reassurance in the midst of an unknown and frankly terrifying event. The only adverse event experienced by both my wife and myself during surgery was that when our son was transferred to a humidicrib, the crib suffered critical failure of its oxygen equipment. Staff then struggled to find another equipped and ready humidicrib which caused us great concern about the welfare of our son. It is simply unacceptable that the Minister for Health, the State Treasurer and RHH have allowed a situation to arise where the NICU does not have sufficient equipment where a failure occurs, and there is a lack of available back up equipment when an infant's life is dependent on said equipment.

8. My wife's aftercare was deeply disappointing. My wife struggled with her recovery, both in relation to pain management and mental health immediately following the surgery. Ultimately, she was not able to get out of bed for 2 days following surgery. Nursing staff were belligerent and unsympathetic in their dealings with her, accusing her of being lazy and simply wanting pain relief (in their view, without proper basis) when in fact she was suffering significant internal bleeding, significant pain in and around the surgical site and post-traumatic stress arising from the traumatic birth and inability to be with her baby following his admission to NICU. From discussions subsequently held with our anaesthetist and OB for the birth of our second child, my wife was advised that it is not uncommon for emergency caesarean patients to struggle with pain relief and recovery following surgery especially where the types of medical conditions (for example, preeclampsia and cholestasis) suffered by my wife are present. My wife also experienced feelings of abandonment and desolation in the first few days following the birth. Regardless of the cause, I strongly believe that this could have been mitigated and better managed had staff shown more

professionalism, understanding of the situation my wife was in, and appropriate mental health and support services had been made available to assist her with her recovery, particularly in circumstances where I was not always with her due to needing to also be present with our son in intensive care

9. Further, to say that nursing staff were unsympathetic and unconcerned to consider whether there may be a medical explanation for her physical weakness, delirium, nausea, loss of appetite, and severe distress would be an understatement – especially given her symptoms were consistent with the blood loss (giant haematoma) she was later diagnosed with experiencing. Instead of prompt, appropriate and objective investigation of her symptoms being undertaken, my wife was made to feel guilty over her lack of quick recovery and getting back on her feet as well as her feelings and postnatal depression being dismissed. Nursing staff generally failed to consult with Dr [redacted] or report her symptomology to him. I raised the issue with nursing staff who largely shrugged off my concerns. Only one nurse spoke with [redacted] briefly prior to her discharge about the need to get further care (from a mental health perspective).

10. The week after my wife's discharge involved symptoms such as high heart rate, inability to sleep, and constant trembling. All of this, we now understand to have likely been a side effect of some medication administered prior to the birth, as well as post-traumatic stress following the circumstances of her caesarean. It wasn't until my wife suffered sudden bleeding from the caesarean wound site (in the RHH bathrooms after visiting our son in NICU) and required a blood infusion and further surgery (due to a haematoma) one week post the birth, that action was taken to remedy the haematoma and address her symptoms. Over a litre of blood was drained from the wound site. By this time my wife was quite pail/greyish in her complexion, a common sign of blood loss. In fact, all of the abovementioned symptoms were indicative of blood loss.

11. We acknowledge that the RHH NICU nurses were exemplary, highly professional, ethical, knowledgeable and compassionate, for the most part. They knew how to work with families in NICU under the often extremely stressful and traumatic circumstances for which those families required attendance at the NICU.

12. However, the bad nurses stood out, through their lack of the temperament and commitment to professionalism that you would expect for a staff member working within NICU where families are going through tragic and terrifying ordeals with their young ones who are born too early, or with severe medical complications. We know this, because during our week stay in NICU, one family suffered the loss of one twin that had been born with complications.

13. During this time, one particularly bad nurse stood out. Her name is [redacted] On Christmas Day [redacted] I was seated beside my child for most of the morning. [redacted] could be heard complaining about wanting to take her break and spent most of her morning audibly gossiping and complaining. She was also not attentive to the prem infants in her care, she was often being slow to respond to beeping alarms.

This nurse particularly stood out to me as being unfit to be in NICU. Her lack of professionalism was so glaring that to this day it stands out in my mind as a marked example of a nursing practitioner that should be struck off.

14. The other nurse that stands out as unprofessional, is a German nurse in special care. She advised my wife that she could not hold our infant during a nighttime visit. The way she said this, caused my wife to breakdown crying. I had to undertake it my self to remove our child from his humidicrib and place him in my wife's arms. Her explanation was that the unit was understaffed and too busy to manage one mother at 10pm at night to hold their child. Skin to skin, and as much of it as possible, is important for prem infants. It is deeply concerning that staffing levels in Special Care are not sufficient.

15. [redacted] also struggled in the postpartum period, with the lack of appropriate advice, and care provided to her in relation to her (unsuccessful) attempts to breastfeed our child, as well as a lack of education and information supplied to her, to allow her to navigate attending Hobart Private in special care each day to care for our son, while he was required to grow and develop (and feed) sufficiently enough to be able to go home. We stayed in NICU, and subsequently Special Care, for 12 weeks (2 weeks post due date) following his birth. This was due to his prematurity and development delay, [redacted] was unable to latch and breastfeed or bottle feed.

16. My wife had been very firm about wanting to breastfeed our child, but found that there was minimal assistance available with this process, nursing and midwifery staff were too quick to offer opinions, and some were physically aggressive with my wife, yanking at her breasts and the baby to try to get it to feed. Their insistence that our baby would just 'get it' eventually and insufficient investigation into the causes of why breastfeeding was not occurring successfully caused significant delay in identifying the cause of the issue. In fact, I rang a family member in Queensland, a qualified senior midwife, whose advice was that our son's case was consistent with cases she had observed in practice of cerebral palsy. In contrast the view of the Tasmanian nursing staff was that they had never seen this issue occur. Clearly there is a lack of experience in feeding and attachment issues, which needs to be remedied.

17. The investigation by nursing staff as to the cause, and appropriate support measures to help our son learn to feed, only occurred within the last 3 weeks of our son's stay in special care. He eventually required specialist assessment by an Occupational Therapist, and we had to teach him to latch (even with a bottle). Our son came home with an NGT intact, due to his delay in being able to latch and properly suck and swallow milk.

18. Had my wife been given appropriate and timely advice about the chances of our son not being able to breastfeed, we might have been able to move to our back-up plan and progress to going home much earlier than we did. The delay added

additional stress to my wife and I who were struggling to cope with being stuck at the Hobart Private Hospital *ad infinitum*.

19. In addition, our son also suffered from significant gastrointestinal discomfort following feedings. This experience meant that he would cry uncontrollably, and extremely loudly for hours on end – without relief. The staff within Special Care and at Hobart Private were largely unhelpful, and often showed frustration at the continual crying, would pressure [redacted] to cease her attempts to breastfeed (when it was time for our son to be fed by NGT) and showed a lack of emotional support or assistance when my wife would struggle to calm our baby following those feeds. On one of the nights where we roomed in prior to going home, our son cried all night. One of the NICU nurses eventually took him off us and commenced swinging him about very roughly in his hospital crib (which was on wheels), in an attempt to silence ("calm") him. My wife was extremely upset by this, and by what she perceived as inappropriately rough handling of our child. Again, we feel that had proper support as well as education / advice provided on how to manage our son's time in special care, we feel we would not have come away from this experience with the same level of trauma and dismay for the medical system.

20. Overall, we acknowledge and express our appreciation to many of the staff we encountered throughout this time, who were all doing an exemplary job, under difficult circumstances and extremely limited resources. However, those few staff who we had bad experiences with, served to contribute to our already existing trauma that arose out of a difficult birth and start to life for our son.

21. In relation to our child's health and allied health management during COVID-19, we would describe access to support and services for premature babies as nearly non-existent. We had a good paediatrician who provided regular support and referrals as needed during our son's first two years. However after his retirement in late 2023, despite there being ongoing medical and developmental issues that we required assistance with, we were not referred to another paediatrician. When we actively sought a referral through our GP, we were advised that there are currently no available Paediatrician's in Tasmania, and that our best chance is to get a referral to someone in Melbourne, again with a long waiting list. While we are financially able to see a paediatrician interstate, it is unacceptable that prematurely born children are left without access to a paediatrician in Tasmania.

22. We also take issue with what we believe in hindsight to be the complete over-reaction and failure of the medical profession to adapt to the spread of COVID-19. While we managed to avoid being in hospital during the lockdowns, we only just arrived home prior to the first lockdown occurring in March 2020. We had limited support (while hospital visits were still required, these were largely restricted, and kept at a distance that did not support full and thorough investigation of our baby), making the experience of seeking medical help for our premature baby a very difficult and frustrating one. We do however want to acknowledge the high

professionalism of the Child Health Nurses, who persisted in providing care during the COVID-19 Pandemic, as well as that of our paediatrician, who made a point of being available to us, as much as was needed and allowed under the circumstances.

23. In relation to general medical care for [redacted] because GP's were declining to see infants with respiratory symptoms, we often had to attend the respiratory clinic. Again, our experience of this was frustrating, as we were all required to keep our distance, and proper thorough examinations of our son were not conducted (in our view) to enable proper diagnosis of any medical issues. On one such occasion, the Respiratory Clinic GP missed significant fluid in our child's ears. My wife and I had noted that during a significant respiratory illness [redacted] was not responding to noises, or having his name called. On further investigation, both his paediatrician and ENT surgeon Dr [redacted] noted the very large fluid build up in our child's ears. This needed to be corrected by surgery and insertion of gromets. Dr [redacted] commented that it was lucky that no damage had occurred to the ear drum despite the large fluid build-up.

24. [redacted] first year involved multiple hospital developmental assessments. Early on, at one of these visits, [redacted] was identified as having absent fidgety movements, and was suspected of having cerebral palsy. He was subsequently referred to St Giles for further assessment and assistance but was subsequently discharged at around 12 months of age, with a finding that he did not suffer from cerebral palsy, but 'only' from developmental delay. This experience contributed to much of the trauma we experienced as his parents in that first year, and added to the stress we felt during any subsequent health assessment (including referrals for both speech delay and developmental delay in the following years). While we acknowledge that the staff we worked with both in the RHH and St Giles, as well as more subsequently Speech Pathology at Hobart Communication Clinic were all exemplary in their dealing with us, the additional and unnecessary stress we experienced in investigating his various medical issues, was exacerbated by the inherent difficulty in navigating the health system (during COVID, with extensive waiting times to see specialists, as well as the lack of available Paediatricians and specialists) in relation to identifying and diagnosing the various medical issues that our son has experienced since his birth.

25. Further, in relation to [redacted] subsequent speech delay I had to offer a blank cheque to numerous speech pathologists to get our child seen to. It was only because another patient dropped out of treatment, that [redacted] was seen within a few short weeks, instead of the original 9 months delay. [redacted] was seen at 2 years of age, instead of 3 years of age because of this. In effect, sparing him a year of delayed development without assistance.

Our recommendations for changes required to improve the current system

- Mandatory trauma informed training for midwifes and nurses to help parents following traumatic / difficult births (especially where mother is not able to be with her child in the first few days, and where mother has to go home without child due to a special care stay), and NICU staff (or employ other staff for this purpose) to provide appropriate mental health services, as well as specialist postpartum advice regarding medical complications that can arise following emergency caesareans, with a view to diagnosing potential medical emergencies (such as haematomas) much sooner, and to assist with realistic advice regarding postpartum issues such as breastfeeding, ability of infants to latch and feed well etc).
- Increased professional development in ethics and ethical duties would greatly assist nursing staff, the same criticisms we (and other respondents) make about nursing staff regarding diagnosis or lack thereof, and lack of appropriate care are strikingly similar to criticisms made by the Coroners Court in cases involving fatalities. In almost all cases of misdiagnosis or failure to diagnose, is an underlying disregard for the patient and their welfare. In our view, disregard for a patient and their welfare stems from ethical failure.
- Additional privacy and support given to mothers required to stay in NICU / Special care where their situation with infant is not 'standard' or typical – for example babies who have severe medical conditions, or are unable to feed (and therefore must stay for longer).
- The addition of support for fathers would also be ideal. Most services in this space are geared towards mothers, but a traumatic experience for a mother and child also affects the father. Moreso when they are left to care for both mother and infant in the weeks following the birth.

Yours sincerely

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