

My dear fellow trustees

I returned from Rio yesterday and pen down here, an initial report on our 7th set of twins.

We undertook the separation surgery on Monday 28th of August, 2023. One of the twins did not survive, and the other twin has been extubated and appears to be neurologically intact and doing well.

To recap, we were referred this set of twins whilst they were some 13 weeks into their gestation, in February 2023. Initial plans were to undertake the separation in stages, starting in December of this year. Towards the latter part of the pregnancy it became clear that one of the twins (Twin 1) had a mono-ventricle of the heart (a serious congenital heart defect). Our cardiology colleagues in Rio, and in London informed us that the chances of long-term survival were small, perhaps in the order of less than 5% and would require multiple cardiac surgery in the first year of life. The twins were delivered via Caesarean section on the 6th of July (at 35 weeks' gestation) due to obstetric concerns. There has since been a heightened degree of anxiety and a push from the medical and ITU teams in Rio, to proceed with the separation surgery. We deferred it as far as we felt it was reasonable. When I arrived there, it transpired that he had had two episodes of cardiac arrest in the preceding few days requiring CPR and emergency separation had been set up but not executed.

The twins were stable the day before the surgery. On the morning of the surgery, twin one sustained, another cardiac arrest and required CPR. He stabilised as the lines were being placed. He then sustained another cardiac arrest and this time CPR took longer and a chest x-ray showed a large pneumothorax. A chest drain was placed but did not have the desired effect. We were informed that it was unlikely they would be able to resuscitate him this time round, and we had to start the surgery expediently, to salvage Twin 2. As you can imagine, a heavy cloud descended into the OR, with this news. We had started the day at 6:30 am, and this news was received at 11:30 am. We started to prep and drape for the surgery. As we were draping, the ITU consultant, who had been looking after these twins in the ITU, continue to fiddle with the chest drain. With the drapes in place, we got a heartbeat once again and Twin 1 stabilised, yet again. This was rather disconcerting, as I, for one, had at this point resigned to the fact that he was dead, and was planning my actions accordingly.

The surgery itself went extremely well. We achieved separation in just over six hours; all the surgical steps went as planned, and we lost a few drops of blood in the entire procedure (estimated combined blood loss 20 mls). Twin 1 weighed 1.9kg and Twin 2, 2.3kgs.

Twin 1, required two or three more episodes of brief CPR during the procedure, but otherwise remain steady in terms of his parameters. Around 1730 (5 hours into the procedure), we were told that they could not resuscitate him anymore. Up until this point, we had still undertaken the surgery with a clear plan to try and salvage both, with the exception of the skin flaps which were drawn to favour Twin 2 (in hindsight, this was not the optimal surgical plan and a clear triumph of hope over reality!).

At the time of his death, the surgery had proceeded without issue hitherto, but now Gabriel and I were struggling to find a plane through the area of conjoined brain and his 'timely' death focused our minds and ensured we did not 'injure' the surviving twin. I realise this the next morning, when I went for a run on the Rio beach, to clear my mind and salve my emotions, the timing of his death could not be 'more perfect' from a purely surgical perspective.

The separation was completed at 1822 and reconstruction completed around 2100 hrs.

Twin 2 was successfully extubated, some 80 hours post surgery and appears to be neurologically intact with good cardiorespiratory parameters.

During the surgery, I was made aware that Twin one had had a peritoneal dialysis catheter placed, in anticipation, as he had never produced any urine. I did not know this beforehand. Renal US were normal. He had also acquired bilateral atelectasis. In the cold light of day, this twin would not have survived long, even if he had pulled through the surgery and perhaps our surgical planning was suboptimal in trying to salvage him as well. From an emotional perspective however, this was perhaps the best course for the parents and the professionals involved. For the twins, I have no idea.

So there we are. The Rio hospital team recorded 'everything' in great details which is excellent. They send me these some pics and a short video which I have attached here. Please do not share. We also had the opportunity to meet up with the last set of twins in Rio and they are making good ongoing progress.

<https://youtu.be/70M6DFMJ710>

So there we are. This is the first CPT child we have lost and whilst the outcome seemed inevitable it is taking sometime to process.

Speak soon

Owase

