

# The Challenges to Fetal Organ Donation – A Case Report

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### Background

There are currently 6035 patients awaiting organ transplantation in the UK<sup>1</sup> and approximately 2% of these are children.<sup>2</sup> Many children who die suffer from diseases or have received therapies that exclude them from being organ donors. Organ donation is only possible when a child dies in hospital, so many children including those who die at home, will not be able to become donors.

A number of pregnancies are affected by anomalies that are incompatible with life which raises the potential for these fetuses to become organ donors. This cannot be considered where there is a chromosomal anomaly, however there needs to be an expectation that the baby will be born alive but not survive more than two to three hours.

Anencephaly is a rare neural tube defect caused by failure of the cephalic end of the neural tube to close between the 23rd and 26th day post conception. This results in failure of the skull and scalp to form and subsequent destruction of brain tissue. Very few Anencephalic babies are carried to full term in the UK.<sup>3</sup>

Approximately a third of these babies show no signs of life at birth, and the remaining infants die in the neonatal period. This makes Anencephaly one of the very few anomalies that may be suitable for consideration of organ donation.

Organ donation from infants with Anencephaly has long been proposed as a viable option with one case of a kidney transplant from an anencephalic donor cited as far back as 1969 in the US.<sup>4</sup> Despite this, there have been very few recent cases of organ donation in the UK from infants with Anencephaly, and fewer still from outside of the UK. Neonatal organ donation raises several ethical dilemmas including prolonging the infant's life to facilitate organ donation at no benefit to the donor. However, it has been deemed ethically acceptable in the UK for organs to be donated from anencephalic infants after circulatory death.<sup>5</sup> Currently, organ donation after brainstem death is not possible in neonates who are less than two months old due to difficulties in confidently assessing the neurological condition of such young infants.<sup>6</sup> In addition, with anencephalic infants it is possible for brain stem function to remain as the brain stem is usually preserved.<sup>5</sup> There are no reliable criteria to diagnose brainstem death in the presence of impaired cerebral development.

Here we present a case of planned organ donation in a pregnancy affected by Anencephaly and a discussion regarding the logistics of arranging organ donation, the relevant screening process and the practical challenges faced.

### Methods

A case report and review of the literature.

### Results

A 32-year-old Afro Caribbean lady presented to University Hospitals Coventry and Warwickshire for antenatal care in her second pregnancy. At her routine dating scan, the baby was noted to be anencephalic. The couple decided to continue the pregnancy and to donate the baby's organs after birth. They received multidisciplinary counselling from the neonatal team, bereavement team and the organ donation team. Plans were put in place to have the organ retrieval team present at birth and to have two theatres available and staffed, one to perform the caesarean section and another to undertake organ retrieval.

Screening took place to ensure the suitability for organ donation and unfortunately the patient was found to have HTLV1 infection and therefore was unsuitable to proceed with the organ donation. She underwent caesarean section at 39 weeks gestation for breech presentation and polyhydramnios and delivered a baby girl. The baby passed away after one hour. At delivery, the baby was noted to have Craniorachischisis (exposure of the entire spinal cord and brain).

### Discussion

The process of arranging organ donation from an anencephalic donor is extensive:

- The parents need to be fully counselled. This is a multidisciplinary process including an obstetrician with an interest in fetal medicine, a neonatologist, and the organ donation team.
- The woman needs to undergo screening tests to check that she is fit for organ donation.
- The process of organ retrieval needs to be set up, including ideally delivery by caesarean section and having a retrieval team ready in a second theatre to take the baby once circulatory death is confirmed.
- The baby needs to show signs of life at delivery but to live no longer than two to three hours.
- Once the baby no longer shows signs of life, they need to be transferred to the second theatre within five minutes to begin the organ retrieval process. The parents need to be prepared for this.

### Conclusion

Organ donation from Anencephalic infants is considered ethically acceptable with parental consent and after circulatory death. Significant practical challenges exist, and the parents need to be made aware of the circumstances in which the baby's organs may not be suitable for donation for example if they are not mature enough or if the infant is born showing no signs of life. In addition, the parents need to be aware that with paediatric organ donation, the organs may not go to a child as there is a much larger number of adult patients awaiting organ transplantation in the UK than children.

In our case, organ donation was not possible due to HTLV1 infection, but this case highlights the challenges and the complex process of organising the donation.

### References

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