

Organ Donation and Babies With Congenital Life-Limiting Conditions

Introduction

There are a small but increasing number of enquiries from clinicians and parents about the possibility of organ donation from small babies with anencephaly and other congenital life-limiting conditions.

NHSBT wishes to be supportive of the parent's wishes for their baby to be an organ donor. However, it is also necessary to be realistic in managing expectations.

Therefore, parents and referring clinicians should be aware that, at present,

1. The only organs that may be transplanted are the kidneys: these will be used en bloc and for a small adult
2. Hepatocytes may be prepared from donated liver and used for transplantation
3. Heart valves may be retrieved if the baby weighs more than 2.5kg
4. More often than not, donation will not be possible, for the following reasons,
 - a. Mode of donation: It may not be possible to mobilise a retrieval team in time if labour is spontaneous. Similarly, donation may be stood down if labour is prolonged. Donation is more likely to be possible if delivery is planned (either through elective Caesarean Section or induction of labour)
 - b. The baby may be stillborn
 - c. As with other forms of DCD donation, the time interval between treatment withdrawal (which is considered to be the point of delivery and placental separation) and asystole may be prolonged.

Responding to the enquiry or referral

Each case should be discussed with the Team Manager/Regional Manager who will liaise with the National Paediatric and Neonatal Specialist Nurse and an initial meeting will be arranged in order to define a clear plan of action. Liaison with the Assistant Medical Director (or in his absence the National Clinical Lead for Organ Donation) will follow this planning meeting and any outstanding items clarified. Subsequent planning meetings will be identified throughout the process as required.

Possibility of transplantation

It is important to establish as soon as possible whether organ transplantation will be considered through consultation with the centres currently supporting neonatal organ transplantation. Currently, Leeds Teaching Hospital is leading on kidney transplantation from neonatal donors but others centres may also undertake this procedure. [FRM5510](#) Neonatal and Infant Donor Assessment and Organ Screening should be used for assessment in conjunction with the information stated below.

Donor hospital multi-disciplinary team

If donation is a possibility, a local hospital team should be established to ensure that the necessary arrangements and safeguards are in place to support the process further.

The team should include:

SNOD Lead - Donation after Antenatal Diagnosis for the region

Hospital CLOD and SNOD

Appropriate clinical specialities as appropriate – obstetrics, midwifery, foetal medicine, neonatology, and palliative care.

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It may be appropriate to inform the hospital governance (such as Head of Nursing, member of the hospital clinical ethics committee)

The role of the team is to

- Define and implement a pathway for donation which is acceptable locally and consistent with national guidance.
- Ensure that consent/authorisation for donation is fully informed and obtained in a timely fashion
- Liaise with the retrieval and implanting teams and ensure that as much information as possible is available to guide donor assessment.

Consent / authorisation

It is vital that parents understand that the likelihood of donation taking place is low and that, while it may only be possible to use the kidneys for organ transplantation, for surgical reasons the kidneys may be retrieved together with liver and pancreas.

Organ assessment

The following information should be made available to the retrieval surgeon

- Ante-natal ultrasound scan
- Report of foetal anomaly scan (performed at 16-20 weeks)
- Presence of urine in the foetal bladder and evidence of any oligohydramnios
- Kidney size
- Estimate of foetal weight (this can be estimated by Ultrasound Scan and should be requested by the maternity team).
- Maternal U&Es
- Evidence of urine production after birth
- HLA typing using cord blood (it may be possible to tissue type the foetus from maternal blood)

Post-donation support

Whether or not donation proceeds, families will need support as is current practice.

Press attention: in some cases, parents or family members have shared their experience on social or other media. Families need to be counselled about the implications and timing of approach in the media. The Press Office should be contacted so that the family can be offered the support they may want or need.

It should be remembered that such donations are also very stressful for the SNODs and retrieval team members and appropriate support may be needed.

Contact numbers

Mr Niaz Ahmad (Renal Transplant Surgeon Leeds Teaching Hospital) via the Renal Transplant Co-ordinators on 0113 2064930 regarding kidney donation.

Liaise with Kings College Hospital regarding hepatocyte donation (Prof Anil Dhawan) via Kings College Liver Co-ordinators 02032999000.