

NHS BLOOD AND TRANSPLANT

**MINUTES OF THE PAEDIATRIC DONATION TELECONFERENCE
HELD AT 2 PM ON WEDNESDAY 16 JULY 2014**

PRESENT: Darius Mirza (Chair)
Elisa Allen
Joe Brierley
Melissa D'Mello
Jonathan Hind
Susan Richards
Kamann Huang

ACTION

Objective:

To present a report looking at a strategy to increase awareness for bowel donation for Neonates and for children under the age of two years at the next BAG meeting on 8th October 2014. The work will include looking at adult bowel donation and examining the current methodology for both paediatrics and adults.

Aims:

- (1) Audit all small and adult donors.
- (2) Improving the education programme for SNODs and CLODs
- (3) Incorporate Transplant Focus Events e.g Transplant Day.
- (4) Look at small donors under two years of age, the national listing criteria and where we are with this.

1 Audit all paediatric and small adult donors:

1.1 Reasons put forward for the low bowel donation rate:

- low consent rate in ICU's down to individual doctors, hospital practice and the healthcare society;
- religious reasons;
- it is more difficult to accept the sudden death of a child. Donation rests solely with the parents;
- there are enough DBD donors but the question is how to obtain them;
- smaller centres are less likely to undertake small bowel transplantation;
- testing for DBD places a big challenge for all neonatal transplant centres;
- the definition of brain stem death within the intensive care community;

ACTION

A working group has been set up to look at the definition of death by the Royal College of Paediatrics and Child Health with a report expected to be released in September. Prof. Neil McIntosh, University of Edinburgh, is leading the study.

Options for increasing bowel donation raised were:

- living bowel donation (it was acknowledged that living liver donation is a life saving option whereas bowel failure can be treated initially without resorting to surgery).
- J Brierley asked about DCD donors – this pool is not utilised for intestinal transplantation. D Mirza suggested taking a small part of the intestines from DCD donors to look at for research purposes. He will liaise with Christian Brailsford who is the lead for research.
- ECMO donation. This is currently monitored and figures are fed back to the Board every year. National data is also kept on the NHSBT website.
- raise paediatric donation within schools. This is currently undertaken in schools in Scotland.

D Mirza

J Brierley recommended attendees to wait for the release of the report from the Royal College of Paediatrics and Child Health before taking any immediate action. J Hind to email K Huang the report for circulation to the paediatric and adult transplant teams.

**J Hind/
K Huang**

2 Improving the education programme for SNODs and CLODs

2.1 S Richards reported that currently recruitment occurs three times a year with the education programme following the same pattern. Going forward recruitment of SNODs and CLODs will take place across the board at the same time with inductions to tie in with the recruitment date. It is hoped this programme will be in operation by October.

There is a plan to change the way sustained education is recorded over a block period of 3 to 4 months starting at the end of this year/beginning of next year.

3 Incorporate Transplant Focus Events

3.1 S Richards has had a discussion with D Gardiner regarding holding short lectures to SNODs and CLODs to increase awareness of the lack of paediatric bowels for donation. D Mirza recommended that a Transplant Focus Day be held in conjunction with stakeholder and Advisory Group meetings.

It was recommended that 'The Transplant Day' held twice a year in May and November, should also be held in the twelve NHSBT regions to incorporate a presentation from the individual transplant centre. S Richards will raise this with D Gardiner. This will be a standing agenda item on the Bowel Advisory Group meeting.

**S Richards
K Huang**

ACTION

The proposal is to have a standard teaching framework to be updated every two years.

4 Looking at small donors under two years of age

4.1 J Brierley reported that no study recording the reason for parents not consenting to organ donation has been undertaken by the British healthcare organisations. J Brierley to provide D Mirza with costs for a research study to be undertaken looking at the consent rate.

J Brierley

It was highlighted that there is a need to change the focus of paediatric donation rather than just concentrate on parents consenting to paediatric donation.