

**NHS BLOOD AND TRANSPLANT
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE**

**THE EIGHTEENTH MEETING OF THE
NHSBT KAG PAEDIATRIC SUB-GROUP ON
WEDNESDAY 26 APRIL 2017, AT 11.00 AM
AT WEST END DONOR CENTRE – BOARD ROOM**

PRESENT:

Dr Stephen Marks (Chair), Consultant Paediatric Nephrologist, Great Ormond Street Hospital
 Ms Anusha Edwards, Transplant Consultant, Bristol
 Dr Ben Reynolds, Consultant Paediatric Nephrologist, Glasgow
 Dr David Milford, Consultant Paediatric Nephrologist, Birmingham
 Dr Graham Smith, Consultant Paediatric Nephrologist, Cardiff
 Dr Helen Jones, Consultant Paediatric Nephrologist, Evelina London Children's Hospital
 Dr Henry Morgan, Consultant Paediatric Nephrologist, Liverpool
 Ms Kate Martin, Statistics and Clinical Studies, NHSBT
 Ms Lisa Mumford, Statistics and Clinical Studies, NHSBT
 Dr Martin Christian, Consultant Paediatric Nephrologist, Nottingham
 Mr Nicos Kessarar, Consultant Transplant Surgeon, GOSH/Guy's/Evelina London Children's Hospital
 Dr Pallavi Yadav, Consultant Paediatric Nephrologist, Leeds
 Dr Rodney Gilbert, Consultant Paediatric Nephrologist, Southampton
 Dr Tracey Rees, BSHI

IN ATTENDANCE:

Mrs Kathy Zalewska, Clinical and Support Services Manager
 Miss Sam Tomkings, Clinical and Support Services

APOLOGIES:

Dr Afshin Tavakoli, Consultant Paediatric Nephrologist, Manchester
 Prof David Talbot, Consultant Transplant Surgeon, Newcastle
 Mr John Connolly, Consultant Transplant Surgeon, Belfast
 Mrs Julia Mackisack, Lay Member
 Mr Khalid Sharif, Consultant Transplant Surgeon, Birmingham
 Dr Mairead Convery, Consultant Paediatric Nephrologist, Belfast
 Mr Mick Stokes, Duty Office Services Manager, ODT
 Dr Nick Plant, Consultant Paediatric Nephrologist, Manchester
 Prof Susan Fuggle, NHSBT Scientific Advisor
 Dr Yincent Tse, Consultant Paediatric Nephrologist, Newcastle

Action

- 1 Decelerations of interest in relation to the agenda- KAGPSG(17)1**
There were no declarations of interest.
- 2 Minutes of the meeting held on the 6 April 2016 – KAGPSG(M)(16)2**
 - 2.1 Accuracy**
The minutes of the previous meeting were agreed as a correct record.
 - 2.2 Action points - KAGPSG(AP)(17)1**

AP1 DCD Kidney Allocation Scheme: Completed – refer to minute 3.
 Check validity of the date on the number of transplants performed using NRP: -

Completed – refer to minute 3.

AP2 Centre Specific Organ Decline Rates: Completed – refer to minute 4.

AP3 Access to Transplant and Transplant Outcome Measures in Children (ATTOMic): Refer to minute 6.

AP4 Proposal for a National Consent Form: Refer to minute 8.

AP5 Academic Pursuits (Update on Abstracts and Publications): Refer to minute 11.

2.3 Matters arising, not separately identified

There were no further matters arising.

3 DCD Kidney Allocation Scheme – KAGPSG(17)2

3.1 Following agreement at the Kidney Advisory Group (KAG) meeting on 9 June 2015, the donor age range within which kidneys are allocated regionally rather than locally, was increased by 5 years on 1 September 2015, and again on 1 September 2016. L Mumford confirmed that the plan in September 2017 is that the age range will be increased again and this will be included as one scheme.

A paper was received showing since the introduction of the new National DCD KAS with 12 children receiving DCD kidney transplants between September 2014 and February 2017.

In table 2, the information recorded shows that HLA matching has improved. K Martin confirmed that three paediatric patients had received a DCD kidney from a donor who underwent normothermic perfusion. K Martin to investigate the kidney function with plasma creatinine and estimated glomerular filtration rate post-transplant for those three paediatric recipients.

K Martin confirmed that the survival analysis data will be included once adequate data has been collected.

K Martin to include creatinine and height into future reports to monitor renal allograft function with estimated glomerular filtration rate as part of patient outcomes.

K Martin

4 Centre Specific Organ Decline Rates – KAGPSG(17)3

4.1 Over the past few years, offer decline rates have been monitored. For paediatric centres, a prospective audit was conducted in 2011 and 2014 examining the reasons for declining offers of kidneys for paediatric patients. This audit is currently being undertaken again in 2017.

The paper received continues to monitor the offer decline rates for paediatric patients. The data obtained, shows Belfast previously had the highest decline rate however last year this has dropped to below the national average. GOSH continue to have the lowest decline rate however this difference is no longer statistically significant.

K Martin to verify the data recorded in table 3 regarding decline rate in 2016 and will redistribute if applicable.

K Martin

The Donor Characterisation working group will be considering which tests should be carried out before the offering of kidney process. This may have an impact on the numbers of organs declined.

Discussion took place on considering organs from high risk donors and the risk of transmitting an infection, and whether this information could be shared with the

recipient prior to being listed on the waiting list. S Marks confirmed that he updated the guidelines for absolute and relative contra-indications for decline of organs for paediatric recipients which were approved by NHSBT PKAG after the changes from SaBTO.

Ongoing work is taking place looking at the outcomes and delays from ongoing work presented at the British Transplantation Society with data on outcomes reported for patients and families (initially trialled in liver transplantation). L Mumford confirmed relative chance of transplant will be amended to take into account DCD changes.

Action**5 2017 Kidney offer decline rate audit – KAGPSG(17)4**

- 5.1 Throughout 2011 and 2014, a prospective audit of the reasons for declining offers of kidneys for paediatric patients was successfully conducted. It was therefore agreed by members, that a third one-year national prospective study should be undertaken in 2017. This audit is currently being distributed to centres and the current return rate is 59%. This audit will continue and K Martin will report on this data until the end of the year, thereafter analysis will take place.

K Martin confirmed a form is required to be completed for each kidney.

Concerns expressed the difficulty of the audit forms being completed by paediatric units if adolescent recipients receiving kidney transplants in adult units. K Martin suggested as she can access the duty office data, she may be able to confirm who declined the offer and forward this information onto to the relevant paediatric nephrologist, who can forward to the appropriate practitioner. The suggestion was made that the Core Donor Form can also be accessed via EOS to retrieve information.

6 Access to transplantation and transplant outcome measures in children (ATTOMic)

- 6.1 S Marks gave a verbal update on the paediatric ATTOMic project which is moving forward based on the ATTOM study which was undertaken in adult units. This is NiHR funded study also using UK Renal Registry data looking at different aspects of patient care of patients on the waiting list for renal transplantation +/- on dialysis or prospective pre-emptive renal transplant recipients.

It has been agreed to commence a pilot questionnaire study of children as of 31 December 2016, which will assist units in pilot data for putting a grant application together (NiHR Programme Grant for Applied Research) for Access to Transplantation and Transplant Outcomes Measures in children (ATTOMic) study:

1. This is a BAPN audit and not a UK Renal Registry project which has the backing of the NHS Blood and Transplant Paediatric Kidney Advisory Group
2. The questionnaire can proceed with the amended form which should be completed for each patient (and can be done alongside the BAPN returns for UK Renal Registry) with closing date in three months of 30 June 2017
3. To simplify the process and to make sure that we have approval from all, we have made the following changes:
4.
 - a. there is no identifiable data so no name, address, hospital numbers etc.

- b. for date of birth, the questionnaire only asks for the month and year so it is no longer identifiable
- c. there is no hospital or ODT recipient number or UKRR number so there can be an allocated local random number (eg.1,2,3 where each hospital keeps their own key) so local identification of patients is possible if more details are required
- d. the e-mailed form will be from nhs.net to the ATTOMIC nhs.net secure account (gos-tr.ATTOMIC@nhs.net) and should be e-mailed securely by 30 June 2017

An email was sent to NHS.net email accounts which included the new form which has been created to collate patient information. G Smith raised the issue of Wales not having access to NHS.net email accounts. S Marks has forwarded the form to individual e-mail accounts as there is no confidential information included.

ATTOMIC Presentation and form delivered to the group.

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| 7 | Update on annual non-favourably matched paediatric grafts – KAGPSG(17)5 | Action |
| 7.1 | Members reviewed a report showing HLA-mismatched kidney transplants performed in the UK between 1 January 2016 and 31 December 2016. In all three cases, the child had waited for more than 365 days prior to transplant. | |

Table 2 shows a summary of mismatch grades for all patients aged under 18 years of age on the kidney transplant waiting list as at 22 March 2017. Of these, further details are provided in table 3 for those who are currently listed for a 221 and 222 mismatched transplant. T Rees confirmed in table 3, the Cardiff mismatch 222 data is a default.

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| 8 | Proposal for a National Consent Form |
| 8.1 | A Edwards updated the group on the progress of trailing the National Consent Form. |

The form consists of three separate sections: a medical section, surgical and confirmation of consent. The form took longer than anticipated to develop, however the form has been sent to 12 families who have been attending the clinic or who have recently had a transplant.

The feedback from the six families who have responded explained the initial interpretation of the form was alarming due to the amount of information included.

Clinicians agreed it is an extensive form to go through with families. A few minor errors have been found on the form.

R Gilbert felt it is a valuable form to include, especially the medical section to discuss with parents.

One colleague suggested including rates, however A Edwards feels this is not required as it was produced as more of a checklist.

It is understood that infoKID has been included in this, although A Edwards will check and amend if necessary.

Anusha would like to extend the trial of this before it is distributed nationally in January 2018.

It was suggested and agreed that the NHSBT logo would preferably be included on the National Consent Form. S Marks has e-mailed J Forsythe to seek approval.

Action

9 NHSBT Kidney Allocation Design

- 9.1 This forms part of the work on the new kidney allocation scheme. In renal transplantation, the child age is classed up until 18 years of age however patients retain their paediatric priority if they are listed before 18 years of age up until they received a renal transplant. Other organs use the age of 16 years to denote reaching adult status. In the previous Kidney Allocation Scheme meetings, the discussion was agreed to consider using a sliding scale as part of the new simulation of age. NHSBT PKAG members agree 18 years of age should be considered "paediatric" cut-off due to access to dialysis.

Members reported many adult centres refusing to see patients unless they are 18 years of age. S Marks explained some adult centres will accept 17 year old patients however this is as a result of local discussions, as some paediatric centres have issues with haemodialysis beds for younger children.

The next Kidney Allocation Meeting will be held on 18 May 2017 to discuss the basic principles. After the meeting is held, future Allocation Meetings will include more representation.

A presentation was given at the British Transplantation Society looking at the Donor Index and the matching of kidneys to recipients. The consensus focused on elderly patients being allocated a 000 kidney when an elderly patient is not likely to outlive the life of a 000 kidney. This is negatively looked upon in the current scheme.

L Mumford explained the use of dual kidneys in the last year has fallen; this is likely to be due to the allocation system.

L Mumford advised the allocation scheme IT programming will start mid to the end of next year. Discussion has not yet taken place regarding age matching.

10 Living Donor Kidney Transplantation 2020 Strategy

- 10.1 Part of the 2020 strategy design will be to harmonise processes nationally and look at learning techniques within adult units.

NHS England is undertaking visits to adult units, however there is no confirmation whether they will incorporate paediatric units. However, HTA are re-auditing paediatric and adult units.

11 Academic pursuits (update on abstracts and publications)**11.1 Academic updates**

- 20 year update: this has yet to be published and another version is being circulated to the co-authors in this group prior to resubmission for publication
- Kidney decline manuscript has been rewritten prior to resubmission for publication.
- PLTD draft has yet to be completed but will be circulated by S Marks with a member of each unit as co-author
- IPTA meeting will be taking place in Barcelona in May 2017 with oral presentations on post-transplant lymphoproliferative disorder, declined kidney data and pre-emptive renal transplantation rates.

Future studies

- ATTOMic
- National consent form
- Abstract submitted by S Marks to ESPN comparing survival for paediatric patients on dialysis and those pre-emptively transplanted.

-L Mumford confirmed re-transplantation rates will be included in the allocation work

- S Marks and N Kessarlis would like to research outcomes in smaller infants versus older children and HLA compatibility in younger and older recipients. K Martin will email S Marks with data held.

K Martin

-As part of the ongoing research into PTLD and other aspects of patient outcomes, the group agreed it would be beneficial to include native nephrectomies with nephrotic syndrome, however this data is not collected within NHSBT, therefore this may have to be captured via Survey monkey.

-B Reynolds informed the group of a Glasgow trainee who would like to undertake research study on tacrolimus variability and adverse effects of tacrolimus as part of a national study. It was discussed that this should be part of the national paediatric nephrology Clinical Studies Group although the trainee would need to collate the data by visiting the centres.

12 FOR INFORMATION ONLY

12.1 **Centre-specific transplant list and transplant activity – KAGPSG(17)6**
Received and noted for information.

13 Any other business

13.1 There were no other items of business.

14 Date of next meeting:

Wednesday 18 October 2017 – teleconference

Organ Donation & Transplantation Directorate

April 2017