

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

**MINUTES OF THE THIRD MEETING OF THE  
PAEDIATRIC SUB-GROUP OF THE KIDNEY ADVISORY GROUP  
HELD ON TUESDAY, 24 NOVEMBER 2009  
IN CONFERENCE SUITE 1, ODT DIRECTORATE, BRISTOL**

<b>PRESENT:</b>	Dr Jane Tizard	Consultant Paediatric Nephrologist, Bristol ( <b>Chair</b> )
	Mr Niaz Ahmad	Consultant Transplant Surgeon, Leeds
	Miss Joanne Allen	Statistician and Clinical Audit, NHSBT
	Mr Francis Calder	Consultant Transplant Surgeon, Guy's Hospital
	Mr Marc Clancy	Consultant Transplant Surgeon, Glasgow
	Dr Sue Fuggle	Scientific Advisor, ODT Directorate – NHSBT
	Dr Andrea Harmer	BSHI Representative
	Mrs Rachel Johnson	Principal Statistician, NHSBT
	Dr Stephen Marks	Consultant Paediatric Nephrologist, GOSH
	Dr David Milford	Consultant Paediatric Nephrologist, Birmingham
	Mr Shahid Muhammad	Patient/Carer Representative
	Dr Mary O'Connor	Consultant Paediatric Nephrologist, Belfast

**In Attendance:** Mrs Kathy Zalewska      Corporate Services, NHSBT (Secretary)

**ACTION****APOLOGIES**

Apologies were received from:

Dr Rodney Gilbert, Consultant Paediatric Nephrologist, Southampton  
 Mr Brian Judd, Consultant Paediatric Nephrologist, Liverpool  
 Dr Heather Maxwell, Consultant Paediatric Nephrologist, Glasgow  
 Mr Justin Morgan, Consultant Transplant Surgeon, Bristol  
 Mr Andrew Ready, Consultant Transplant Surgeon, Birmingham  
 Mr Hany Riad, Consultant Transplant Surgeon, Manchester  
 Prof David Talbot, Consultant Transplant Surgeon, Newcastle  
 Dr Kay Tyerman, Consultant Paediatric Nephrologist, Leeds  
 Dr Judith van der Voort, Consultant Paediatric Nephrologist, Cardiff  
 Dr Alan Watson Consultant Paediatric Nephrologist, Nottingham  
 Mr Alun Williams, Consultant Transplant Surgeon, Nottingham

**1      DECLARATIONS OF INTEREST IN RELATION TO THE AGENDA –  
KAGPSG(09)13**

1.1      There were no declarations of interest for this meeting.

**2      MINUTES OF THE PREVIOUS MEETING HELD ON 11 JUNE 2009 –  
KAGPSG(M)(09)1**

2.1      The minutes of the meeting held on 11 June 2009 were agreed as a correct record.

**3      ACTION POINTS ARISING FROM THE PREVIOUS MEETING –  
KAGPSG(AP)(09)2**

3.1      **Item 1 – Access to paediatric renal transplantation:** Work is in hand for details of the frequency of antigens in the donor pool to be prepared and circulated to Centre Directors and Heads of Laboratories.

**S Fuggle**

**Item 2 – Reallocation of kidneys through centre choice:** Refer to minute 4.2.

**Item 3 – Reasons for decline of kidney offers for paediatric patients:** A review of the detail submitted by centres is referred to at minute 5. Work is in hand on the inclusion of a new reason for decline on the Duty Office pick-list to record that a kidney offer has been declined due to a live donor offer. This will form part of a wider review for monitoring the new retrieval arrangements from April 2010.

**Item 4 – Assessing missed offers for paediatric patients in Tier D:** Refer to minute 6.2.

**Item 5 – Impact of change to 2006 kidney allocation scheme on long-waiting paediatric patients:** Refer to minute 6.1.

**Item 6 – Schooling and education in paediatric renal patients:** This item is in hand and will be referred to the next meeting of the BAPN executive.

**Item 7 – Transition of patients from paediatric to adult services:** Work is in hand to meet and agree a protocol specifying the data that needs to be collected. Arrangements will be made for representatives to attend the Registry meeting to take this work forward. Work is also in hand to add the date of transfer to the relevant data collection forms.

**Item 8 – AOB:** This work will be included as part of the meeting at Item 7 above.

J Tizard

#### 4 CLINICALLY URGENT PATIENTS

##### 4.1 Protocol for clinically urgent scheme for paediatric patients awaiting renal transplantation – KAGPSG(09)14

4.1.1 At the last meeting of the Kidney Advisory Group the priority allocation of kidneys to clinically urgent patients was agreed subject to the development of a formal protocol. A protocol was submitted to the sub-group for approval whereby a child may be priority listed for the next eligible blood group compatible donor in the following situation:

- In the event of potential imminent or actual loss of dialysis access without which the child will not survive
- In a child with functioning dialysis but no alternative dialysis access and where dialysis access is likely to become difficult within a short period and when special restrictions are required for a suitable kidney (eg size due to anatomical difficulties in the recipient), which significantly restricts the possibility of an appropriate donor.

Following discussion, minor amendments to the protocol were agreed as follows:

- A child may be priority listed for the next eligible blood group compatible donor (for tiers A – E) *under the age of 50, regardless of match grade.*
- *Options for live related donation have been considered and excluded.*

Agreement to activate the patient with a priority listing should be given by the Chair of the Paediatric sub-group together with at least one other member of the committee. The protocol should also state that the process will be monitored and audited by NHSBT.

J Tizard agreed to amend the protocol and submit this to the next meeting of the Kidney Advisory Group for endorsement. Once the protocol is endorsed by KAG, J Tizard will arrange for details of the protocol and contact list to be emailed to the sub-group membership to ensure they are happy to be contacted, and will email all sub-group members to ask if there are any

J Tizard

patients who fulfil these criteria.

It is the responsibility of each centre to maintain their own list for this clinically urgent scheme and to promote these patients as necessary.

**Post meeting note:** *The protocol was endorsed at KAG subject to the caveat that regular monitoring of the scheme is undertaken to ensure that it is not abused by centres.*

#### 4.2 **Reallocation of kidneys through centre choice – KAGPSG(09)15**

- 4.2.1 Members received a letter which was recently sent to paediatric renal centres by J Tizard regarding the reallocation of kidneys through centre choice. On occasions a kidney will be accepted by a centre for a named patient who subsequently cannot receive the transplant. If the kidney has already been despatched and there are no patients nationally in tiers A to D or 20 hours of cold ischaemia time have passed then the centre can use the kidney in the most appropriate patient from their local list. Following a review of the first three years of the new allocation scheme it was highlighted that 207 of the 413 donors who were under the age of 50 years and were accepted but not used in the intended adult patient would have been suitable for paediatric patients. Paediatric centres had therefore been asked to draw this to the attention of their local tissue typing group or whoever identifies potential recipients to make sure that in the event of a kidney being available for local use that paediatric patients are considered for these kidneys, although centres are encouraged to use the matching run as an order. S Fuggle suggested that this letter should be forwarded to the Heads of the relevant H & I laboratories to highlight this issue. An update report will be submitted to the next sub-group meeting.

**Corporate  
Services**

#### 5 **REASONS FOR DECLINE OF KIDNEY OFFERS FOR PAEDIATRIC PATIENTS – KAGPSG(09)16**

- 5.1 A paper was received on the reasons for decline of kidney offers for paediatric patients. Donor unsuitable due to size mismatch tends to be as a result of lack of surgical expertise in paediatric transplants, particularly in Birmingham and Belfast. It was recommended that representatives from these centres discuss with their colleagues the options available to improve this situation, eg offers of training with other centres or the listing of small patients elsewhere. Members noted that Birmingham was already trying to address the situation and had lifted its weight restriction, which will be kept under review. In addition, some patients have been transplanted elsewhere if surgeons have been uncomfortable performing transplants from live donors. The group also acknowledged the difficulty for new surgeons in becoming competent in paediatric transplants and F Calder stated that Guy's would welcome any surgeons wishing to observe a paediatric transplant as part of their live donor programme. J Tizard also agreed to discuss with both the BAPN and the BTS the possibility of running a paediatric transplantation workshop.

**J Tizard**

Of the six offers declined because the donor was deemed unsuitable due to cause of death members noted that it is difficult to know how many of these were the actual cause of death and it was recommended that further analysis take place on those listing 'encephalitis' or 'presumed encephalitis' as cause of death.

Those offers declined due to donor past history tend to have more than one reason listed. In the majority of centres the decision on whether to accept is taken by the surgeon after liaison with the nephrologist. It was noted that in

Birmingham, which had the highest decline rate due to donor past history, the nephrologist is not involved in the decision-making process. Following discussion it was recommended that offers should not be declined on the basis of alcohol abuse alone or a family history of diabetes. It is not absolutely necessary to decline even if the donor was diabetic but this would depend on length of diabetes and cause of death. It was acknowledged that this data is sourced from the base hospital of the donor and may not necessarily relate specifically to the kidney as the donor may have been a multi-organ donor. R Johnson added that reason codes are currently being reviewed and it may be that these need to be more specific.

Outlying donors in the histograms relating to height/weight were discussed. It was noted that in one case it was, in fact, the recipient and not the surgeon who had declined the offer and this should have been reported more accurately.

Members highlighted the need for guidelines for paediatric surgeons and nephrologists in terms of what can be transplanted and what can be treated if transplanted as there is currently considerable variability between centres in offers being accepted or declined. F Calder agreed to circulate a publication on the risks for HBCAB.

F Calder

## 6 PAEDIATRIC PRIORITY IN KIDNEY ALLOCATION SCHEME

### 6.1 Impact of changes to 2006 kidney allocation scheme on long waiting paediatric patients and patients turning 18 on the list – KAGPSG(09)17

6.1.1 A paper was produced with the aim of determining whether changes to the scheme have had the desired effect of transplanting long-waiting paediatric patients and patients retaining 'paediatric priority' beyond 18 years of age. Although no long waiting paediatric or 'paediatric priority' patients had received a transplant in Tier D as a direct result of additional waiting time points in place since 15 July 2009, one patient had received a transplant in Tier D since that date and patients are achieving a higher rank than they would have previously. Long waiting paediatric patients continue to achieve a high ranking and receive transplants in Tier E. Three patients on the list who were awarded 'paediatric priority' status have received a transplant as a result of the change to the scheme for patients turning 18 on the list. Of the few long-waiters on the list it was noted that one in Birmingham had now had the weight restriction lifted.

Members welcomed the report and the positive outcomes from the changes to the scheme. Transplants in long waiting paediatric patients and patients awarded 'paediatric priority' will continue to be monitored.

### 6.2 Comparison of adult and paediatric kidney only simultaneous pancreas/kidney transplants – KAGPSG(09)18

6.2.1 The sub-group had previously expressed concerns that paediatric patients in Tiers D and E are being disadvantaged by the priority given to adult kidney only (KO) patients in Tier D and to simultaneous pancreas/kidney (SPK) patients. J Allen submitted a paper on this issue and discussion took place on whether there is greater justification for recommending that paediatric patients in Tier D should rank higher among the adults in that tier than there is for recommending that more kidneys currently used for SPK transplantation should be allocated to paediatric patients. It was agreed to submit a simpler version of this paper to KAG requesting consideration of an adjustment to the points scoring system applied in Tier D to provide greater priority to favourably

J Tizard/  
J Allen

matched paediatric patients.

**Post meeting note:** The paper was agreed in principle at KAG and A Hudson will liaise as required to implement the change and report back to future meetings of both this sub-group and KAG.

A Hudson

## 7 FACTORS INFLUENCING WAITING TIME TO PAEDIATRIC TRANSPLANT – KAGPSG(09)19

7.1 Concerns had previously been expressed about increasing waiting times to kidney transplant for paediatric patients and a paper was produced with the aim of identifying factors influencing waiting time to transplant and to identify any differences between centres after adjusting for these factors. J Allen agreed to split Table 5 (Factors influencing paediatric patients receiving a KO transplant within a year of active listing) into separate time periods for Belfast. Due to the large variety of match grades being requested it was agreed to send centre specific information to each paediatric centre requesting that they check that patients are listed for an appropriate match grade. If they are currently listed for anything less than a favourable match with an easy to match tissue type and have been waiting less than one year then the reason for this should be reported. In addition centres should be asked to review those patients who have very strict listing criteria and to advise if these can be relaxed.

J Allen

J Allen

Members noted that a registry of ABOi transplantation has been established to guide practice, although few paediatric patients have been transplanted to date.

There are three articles due to be published shortly in Transplantation on the allocation algorithm which do include limited data on paediatric transplantation. It was recommended that a follow-on paper should be prepared, focusing on how the scheme has evolved for paediatric patients together with waiting times and other factors that have influenced patients waiting. This paper could then subsequently be submitted to Transplantation for publication or perhaps to NDT(Nephrology Dialysis Transplantation). J Tizard would take this suggestion forward via the BAPN executive.

J Tizard

## 8 LINK BETWEEN RENAL REGISTRY AND NHSBT

8.1 J Tizard agreed to liaise with Carol Inward, chair of the Paediatric Renal Registry, regarding the formation of links with NHSBT re paediatric data.

J Tizard

## 9 FOR INFORMATION ONLY:

### 9.1 SaBTO H1N1 Guidance

9.1.1 Members noted the guidance from SaBTO on the H1N1 virus.

## 10 ANY OTHER BUSINESS

10.1 The renal transplantation recipient cost template is based around a standard deceased donor adult transplant and does not apply to paediatric transplantation. Members were not aware of any plans for similar work on commissioning costs within the paediatric community.

10.2 Transplant 2013 is a paper establishing a coalition of stakeholders for the promotion of transplantation and increasing the number of donors. The BTS is also involved with this. J Tizard agreed to find out further information on this.

J Tizard

10.3 Members noted that the statistical support for the sub-group would be changing over the next few months as J Allen was due to take maternity leave. Alex Hudson will be taking on the statistical support for renal transplantation with Lisa Mumford concentrating on paediatric issues.

**11 DATE OF NEXT MEETING**

11.1 The next meeting will take place on Wednesday, 28<sup>th</sup> April 2010, commencing at 11 am at NHSBT Filton.