

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

**MINUTES OF THE FOURTH MEETING OF THE
PAEDIATRIC SUB-GROUP OF THE KIDNEY ADVISORY GROUP
HELD ON WEDNESDAY, 28 APRIL 2010
IN MEETING ROOM 1, NHSBT FILTON, BRISTOL**

PRESENT:	Dr Jane Tizard	Consultant Paediatric Nephrologist, Bristol (Chair)
	Miss Lisa Mumford	Statistician and Clinical Audit, NHSBT
	Mr Francis Calder	Consultant Transplant Surgeon, Guy's Hospital
	Dr Sue Fuggle	Scientific Advisor, ODT Directorate – NHSBT
	Dr Andrea Harmer	BSHI Representative
	Mr Alex Hudson	Statistician and Clinical Audit, NHSBT
	Mr Brian Judd	Consultant Paediatric Nephrologist, Liverpool
	Dr Stephen Marks	Consultant Paediatric Nephrologist, GOSH
	Dr Heather Maxwell	Consultant Paediatric Nephrologist, Glasgow
	Dr David Milford	Consultant Paediatric Nephrologist, Birmingham
	Mr Hany Riad	Consultant Transplant Surgeon, Manchester
	Prof David Talbot	Consultant Transplant Surgeon, Newcastle
	Dr Judith van der Voort	Consultant Paediatric Nephrologist, Cardiff
	Mr Alun Williams	Consultant Transplant Surgeon, Nottingham
In Attendance:	Mrs Kamann Huang	Corporate Services, NHSBT (Secretary)
	Miss Trudy Monday	Corporate Services, NHSBT (Secretary)

ACTION**APOLOGIES**

Apologies were received from:

Mr Niaz Ahmad, Consultant Transplant Surgeon, Leeds
 Mr Marc Clancy, Consultant Transplant Surgeon, Glasgow
 Dr Rodney Gilbert, Consultant Paediatric Nephrologist, Southampton
 Mrs Rachel Johnson, Principal Statistician, NHSBT
 Mr Justin Morgan, Consultant Transplant Surgeon, Bristol
 Mr Shahid Muhammad, Patient/Carer Representative
 Dr Mary O'Connor, Consultant Paediatric Nephrologist, Belfast
 Mr Andrew Ready, Consultant Transplant Surgeon, Birmingham
 Dr Kay Tyerman, Consultant Paediatric Nephrologist, Leeds
 Dr Alan Watson Consultant Paediatric Nephrologist, Nottingham

**1 DECLARATIONS OF INTEREST IN RELATION TO THE AGENDA –
KAGPSG(10)1**

1.1 There were no declarations of interest for this meeting.

**2 MINUTES OF THE PREVIOUS MEETING HELD ON 24 NOVEMBER 2009 –
KAGPSG(M)(09)2**

Accuracy

2.1 The minutes of the meeting held on 24 November 2009 were agreed as a correct record.

2.2 **Action points arising from the last meeting – KAGPSG(AP)(10)1**

Item 1 - Access to paediatric renal transplantation: This work is being undertaken by Joanne Allen in Stats who is currently on maternity leave. This will be on hold until her return in August and placed on the agenda for the next meeting.

Corporate
Services

Item 2: Schooling and education in paediatric renal patients: BAPN agreed that this issue does not fall under the remit of the paediatric subgroup of KAG. The BAPN are currently defining networks in nephrology and education will be considered within this, therefore this item can be taken off the agenda.

Item 3: Protocol for clinically urgent scheme for paediatric patients awaiting renal transplantation: The protocol has been amended, submitted to the Kidney Advisory Group and endorsed by KAG members. Members agreed that the nephrologist should be the first port of call. Corporate Services will email details of the protocol and contact list to the sub-group members to see if any patients would be listed in this category. All contact addresses are to be listed within NHSBT. It was noted that any child placed on the clinically urgent scheme should have been discussed with the local surgeon first.

Item 4: Reallocation of kidneys through centre choice: All centres and H & I laboratories have been written to regarding the issue of the number of kidneys re-allocated to adults when deemed not suitable for transfer to other centres. It was highlighted that a regular report of whether any of these kidneys were transplanted to children was required. NHSBT to provide an annual report.

L Mumford

Item 5: Reasons for decline of kidney offers for paediatric patients: Some kidneys have been refused due to size and mis-match in small recipients. David Talbot to liaise with Alun Williams regarding setting up a half day paediatric transplantation workshop for this. It was agreed that this might link with the Surgical Challenges meeting which is to be held in Newcastle this year.

D Talbot

Francis Calder has circulated a publication on the risks for HNCAB which will be fed into a subsequent project looking at issues around acceptance/refusal of kidneys for transplantation.

Item 6: Comparison of adult and paediatric kidney only simultaneous pancreas/kidney transplants: The issue of ensuring children are not disadvantaged by pancreas/kidney transplants has been addressed by giving children greater priority in Tier D.

Item 7: Factors influencing waiting time to Paediatric Transplant: It was reported that different centres use different matching criteria at listing. Most centres had responded to the enquiry re appropriate listing for easy to match children. Optimal timing of listing pre-emptively is not known and KAG Paediatric sub-group members could work on a project with the Renal Registry regarding this issue. It was suggested that the Birmingham listing criteria could be adapted as guidance (see minute 2.3).

Item: 8: Link between Renal Registry and NHSBT: Rachel Johnson and Jane Tizard had a meeting at the Renal Registry which indicated good support for collaboration. Data from the Renal Registry and others at the moment shows a problem with following paediatric data through to adulthood. There is a proposal to back a project to link this for every patient but there are staffing issues around this.

Item 9: Any other business: Jane Tizard has circulated the paper on Transplant 2013 to promote it. The paper aims to increase organ donation by 50% by 2013 asking for support from various organisations. However the BAPN cannot give financial support for this. Simon Waller who sits on the BAPN will represent the KAG Paediatric Sub-Group at the Transplant 2013 AGM.

2.3 **Matters arising not separately identified:**

Minute 5.1: Centre policies on accepting/refusing kidneys - It was highlighted that there had been reports of surgeons accepting/refusing kidneys without discussing with the nephrologists first. Following an email survey this does not seem to be a frequent problem. Jane Tizard reported that she has received feedback that surgeons and nephrologists are now communicating with each other in the centre where it was originally reported

Minute 7.1 :**Matching criteria – AP7a**

After discussion it was agreed to set up guidelines on matching criteria using the paper produced by David Milford as a base.

- It was agreed that while a guideline for suggested matching criteria could be developed, matching criteria do need to be discussed on an individual basis, preferably at a monthly meeting between clinicians and tissue typing team. The guideline is to include the paragraph: "It is recommended that all patients are to be discussed with the local tissue typing representative."
- If a child is listed for a full match because they are waiting for LRD, this should be identified.

Email the paper to members for comment.

D Milford

- Centres should also be written to reminding them of what is a favourably matched kidney (currently some consider **0=2 as favourable).

J Tizard

Jane Tizard also highlighted that it would be helpful to have an updated list of the frequency of antigens to help the nephrologists/tissue typists to list patients for appropriate mismatches. Sue Fuggle agreed to provide this. Sue Fuggle highlighted that matching criteria for individual patients should be set in conjunction with the local tissue typing laboratories.

S Fuggle

Minimum match grade summary – AP7b

There is variance and confusion across the country on this issue at present. We have written to everyone to check if they were fulfilling the matching criteria, which should be a 110 match for children with easy to match tissue type (ie \leq match point 5. Kidneys are easy to match which should not be less than a 110 match for the first year of listing.

3 ALLOCATION**3.1 Update on the clinically urgent scheme**

This is currently in the IT queue for development and will be prioritised for the next meeting in November.

3.2 Prioritising paediatric patients in Tier D - KAGPSG(10)2

A Hudson was introduced to members, replacing Rachel Johnson, as the statistician responsible for kidney transplantation

There are two distinct groups. One is the adult patients and the other paediatric patients. Alex Hudson produced 3 simulations to look at improving allocation priorities for paediatric patients. These were:

Simulation (a) – 2006 scheme baseline simulation

Simulation (b) – Prioritise all children above all adults in Tier D

Simulation (c) – Upgrade paediatric HLA/Age scores within Tier D

If paediatric patients in Tier D are upgraded in terms of HLA/Age score, then the likely result is for paediatric patients to more commonly appear above adult patients within Tier D without causing any significant impact on the adult kidney

programme. Standard listing criteria are being considered across all of the Advisory Groups. Jane Tizard congratulated Alex Hudson on the simulations produced, and members agreed that they were happy for Alex Hudson to implement Simulation (c) which is anticipated to take around 6 months. Andrew Bradley has also seen this paper, which will be taken to the next KAG meeting.

3.3 **Summary of three and nine months KAS report - KAGPSG(10)3**

The number of patients transplanted since the introduction of the new scheme is similar to the prediction. The waiting times are also broadly similar, with 91% being less than 3 years. There are fewer patients on the waiting list who have been waiting for more than 3 years. However the number of patients in the 0-5 year age group has doubled over the last 5 years. The median waiting time between October 2004 and April 2006 was 296 days, whereas it was 367 days between April 2006 and Dec 2008. However there have been changes to the scheme which should now start to show a benefit.

Regarding centre activity offers, there has not been any significant variation in the last four years of the proportion of offers declined within each centre; however the number of offers declined does vary across centres. Lisa Mumford agreed to look into those centres that turn down more offers and compare the refusal rate of kidneys with the listing criteria from the November 2009 paper and find out if those centres are listing patients with lax matching criteria which lead to the offered kidneys being declined due to an unsuitable match.

L Mumford

3.4 **Non-age related reasons for prioritising paediatric patients - KAGPSG(10)4**

Members received a paper listing reasons for prioritising paediatric patients, which has been requested by James Neuberger as all allocation algorithms need to be justified to the lawyers based on clinical evidence to overcome the issue of age discrimination in transplantation.

Jane Tizard will amend the above paper with the following alterations:

- remove the line "HD lines used" as this process is more difficult to perform in children.
- Paediatric units often so far away that may have to travel up to 400 miles and have HD all in one day - rewrite sentence to clarify.

J Tizard

4 **PROJECT PROPOSAL: A REVIEW OF PAEDIATRIC KIDNEY TRANSPLANTATION IN THE UK - KAGPSG(10)5**

4.1 Following a review of the paper presented at the meeting by Lisa Mumford, members proposed including the following additional areas for analysis:

- Sensitisation
- PTLD (cancer)
- Post transplant Diabetes
- Donor cause of death

L Mumford

5 **COLD ISCHEMIA TIME ANALYSIS OF PAEDIATRIC TRANSPLANTS – KAGPSG(10)6**

5.1 Members received a paper on the audit of cold ischaemia time (CIT) of transplanted kidneys in paediatric patients across centres for both locally used and imported kidneys. Over the last four calendar years the average CIT has remained constant at around 16.1 hours. All centres have a similar average CIT for paediatric kidney only transplants retrieved locally, whereas for imported paediatric kidney only patients Belfast and Glasgow both show higher than average CIT. This is not unexpected for geographical reasons.

It was asked whether the issue of virtual cross matching should be investigated in children. Hany Riad reported that this has already been investigated in Manchester over the last year. Problems arising have been around access to theatre, although it was highlighted that this factor depends on the local centre's

practice.

Sue Fuggle, Andrew Bradley and Craig Taylor are currently writing an article for publication around these issues.

Hany Riad agreed to email the Cambridge protocol on virtual cross-matching for transplantation to members/centres.

H Riad

6 THE USE OF NON-FAVOURABLY MATCHED GRAFTS - KAGPSG(10)7

6.1 Lisa Mumford presented this paper to members, reporting that centres are adhering to the criteria for low matchability points.

7 IMPROVING THE FORMAT OF THE CUSUM REPORTS FOR MONITORING PAEDIATRIC KIDNEY TRANSPLANT OUTCOMES - KAGPSG(10)8

7.1 Alex Hudson outlined the changes which have been made to improve the format of the CUSUM reports.

A couple of changes will be seen in the next reports. The first is the introduction of a new chart called the tabular CUSUM. When there is a signal a CUSUM will be indicated by a black dot with a target line for the CUSUM to cross before the signal is shown. The advantage of this is a centre can be pre-warned when they are approaching a signal. Once the signal is triggered then the CUSUM returns to the base line. The centre's expected failure rate (based on its past failure rate) governs the degree of the downward slope after a signal has been set off and can be used to measure the change in a centre's practice.

The second change is to simplify the kidney charts in line with the pancreas CUSUM charts and to introduce a column on patient mortality on the left hand side with graft failure on the other.

8 NON-USE OF PAEDIATRIC KIDNEYS

8.1 Reasons for decline of kidney offers for paediatric patients - KAGPSG(10)9

An update of the paper for the financial year 1 April 2009 – 31 March 2010 was received.

Most reasons for decline of kidney offers for paediatric patients are due to history and size. Jane Tizard had written to Belfast regarding the issue of decline due to donor /recipient mismatch in size. Birmingham has addressed the problem with new surgical input. On this occasion Bristol also had declined a significant number due to size but it is thought that this related to a single patient with difficult anatomy. David Milford from Birmingham reported that a transplant patient aged 16 years comes under data transplants for adults so the data is not captured under paediatric transplants.

Jane Tizard highlighted the need to develop guidelines regarding indications and contra-indications for accepting a kidney (see minute 8.2).

Members of the meeting are to look at their own centres for the reasons for decline of kidney offers.

All

8.2 Development of guidelines on accepting kidney offers for paediatric patients - KAGPSG(10)10

These guidelines are a starting point regarding issues around why kidneys are declined. They are being reviewed at the moment. It was agreed that it would be helpful to have a comprehensive report including a summary (eg. 2-3 sides of A4) using the framework presented at the meeting. This report would also be helpful to share with patients.

David Milford, Stephen Marks and Hany Riad to liaise and put forward a report at the next meeting.

D Milford/
S Marks/
H Riad

Trudy Monday to email the above document KAGPSG(10)10c to David Milford. **T Monday**

8.3 Current reasons for declining offers - KAGPSG(10)11

Members received the list of current reasons available for declining offers. It was suggested that there could be a paediatric section, including donor reasons, recipient reasons, etc. Jane Tizard asked members to liaise to make suggestions for 'reasons for decline'.

J Tizard

David Milford, Stephen Marks and Hany Riad to produce a document listing the reasons for declining kidney offers.

**D Milford/
S Marks/
H Riad****9 NON-HEARTBEATING DONATION**

9.1 Heather Maxwell reported on an incident which arose around DCD donation, where all organs from a paediatric donor were declined. It was highlighted that guidelines for DBD donation of kidneys are for donors aged five years old and over, and that this should be the guideline adhered to for DCD donor offers. There is not enough information available to make alternative conclusions from current guidelines, therefore the current guidance should be adhered to.

10 FOR INFORMATION ONLY:**10.1 Centre-specific waiting list and transplant activity - KAGPSG(10)12**

10.1.1 No comments were received.

10.2 BTS paediatric waiting time slides - KAGPSG(10)13

10.2.1 No comments were received.

10.3 Factors influencing waiting times to paediatric transplant – KAGPSG(10)14

10.3.1 No comments were received.

10.4 Update on requested allocation – KAGPSG(10)15

10.4.1 No comments were received.

11 ANY OTHER BUSINESS

11.1 There were no further items raised.

12 DATE OF NEXT MEETING

12.1 The next meeting will take place on Wednesday, 3rd November 2010, commencing at 11 am, at ODT in Bristol.