NHS BLOOD AND TRANSPLANT
ORGAN DONATION & TRANSPLANTATION DIRECTORATE

MINUTES OF THE FIRST MEETING OF THE PAEDIATRIC SUB-GROUP OF THE KIDNEY ADVISORY GROUP HELD ON WEDNESDAY, 22 OCTOBER 2008 IN CONFERENCE SUITE 2, ODT DIRECTORATE, BRISTOL

PRESENT:		
	Dr Jane Tizard	Chairman
	Mr Niaz Ahmad	Consultant Transplant Surgeon, Leeds
	Mr Francis Calder	Consultant Transplant Surgeon, Guy's Hospital
	Mrs Rachel Johnson	Principal Statistician, ODT Directorate - NHSBT
	Dr Brian Judd	Consultant Paediatric Nephrologist, Liverpool
	Dr Stephen Marks	Consultant Paediatric Nephrologist, GOSH
	Dr Susan Martin	Deputy for Dr Andrea Harmer, BSHI Representative
	Dr David Milford	Consultant Paediatric Nephrologist, Birmingham
	Mr Justin Morgan	Consultant Transplant Surgeon, Bristol
	Mr Shahid Muhammad	Patient/Carer Representative
	Dr Mary O'Connor	Consultant Paediatric Nephrologist, Belfast
	Mr Hany Riad	Consultant Transplant Surgeon, Manchester
	Prof Alan Watson	Professor of Paediatric Nephrology, Nottingham

In Attendance:		
	Miss Joanne Allen	Senior Statistician, ODT Directorate – NHSBT
	Miss Sue Pioli (CUSUMs)	Senior Statistician, ODT Directorate – NHSBT

ACTION

APOLOGIES

Apologies were received from:

Dr Sue Fuggle	Scientific Advisor, ODT Directorate - NHSBT
Dr Rodney Gilbert	Consultant Paediatric Nephrologist, Southampton
Dr Heather Maxwell	Consultant Paediatric Nephrologist, Glasgow
Prof David Talbot	Consultant Transplant Surgeon, Newcastle
Dr Judith van der Voort	Consultant Paediatric Nephrologist, Cardiff

1 WELCOME AND INTRODUCTIONS

1.1

2 DECLARATIONS OF INTEREST IN RELATION TO THE AGENDA – KAGPSG(08)1

2.1 There were no declarations of interest.

3 TERMS OF REFERENCE AND CHAIR OF SUB-GROUP - KAGPSG(08)2

3.1 Terms of Reference to be revised to state membership of the group, ie a nephrologist or surgeon from each paediatric centre, with the intention that a second nominated person from each centre would deputise as required. Each representative would therefore be a member of the group **J Tizard**

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	for three years, and deputise for three years. In addition to centre representatives, a BAPN KAG link, BSHI representative, patient/carer representative, NHSBT scientific advisor, Medical Director, Statistician and Corporate Services Officer are included in the membership.	
3.2	The original intention was to have an annual meeting and use email correspondence for discussion between meetings. The group agreed that the Paediatric Sub-group should meet every six months as per the other Advisory Groups. Mrs Johnson would check that funding would be available for this.	**R Johnson**
3.3	Dr Tizard invited expressions of interest for Chairmanship of the Paediatric Sub-group to be emailed to her. Dr Tizard stated that she was happy to chair the group in the absence of other interest.	**All**
4	**KIDNEY ALLOCATION SCHEME**	
4.1	Mrs Johnson presented a summary of the rationale behind changes to the kidney allocation scheme, how the scheme works and results observed since the scheme was introduced in April 2006.	
	Within Tier D (000 mismatched ‘other’ adult patients and favourably matched paediatric patients (100, 010, 110 mismatches), there was some concern that paediatric patients are possibly being disadvantaged because the adult patients within this tier are awarded more HLA-age points than the paediatric patients. The enhancement to the scheme made in April 2008 was also noted in that paediatric patients waiting more than two years automatically get an increase in points in Tier E. Twelve long waiting paediatric patients have already benefitted from this.	
	There was some concern over size matching, ie transplanting large adult kidneys into small paediatric patients. ODT to perform analysis looking at weight and height, incorporating other factors such as cold ischaemia time and age.	**R Johnson**
	If there are any other thoughts or suggestions regarding paediatric patients in the kidney allocation scheme, please send an email to Dr Tizard.	**All**
5	**PRIORITY IN KIDNEY ALLOCATION FOR PAEDIATRIC PATIENTS TURNING 18 WHILE ON THE TRANSPLANT WAITING LIST – KAGPSG(08)3**	
5.1	This was discussed and accepted at the last Kidney Advisory Group, with the revision that patients do not need to have been on the active list for three months prior to the age of 18 years, they just need to have been active at some point prior to turning 18. The group agreed with this, although there was some concern regarding the unfairness for a patient over the age of the 18 who is dialysed potentially losing out to a patient who was pre-emptively listed before they turned 18. The scheme will be monitored to ensure centres are not abusing the system. It will be implemented as soon as possible, but no firm date could be given.	**R Johnson**

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6 CHANGE TO LOWER DONOR AGE LIMIT FOR KIDNEY/PANCREAS DONATION

6.1 Kidney/pancreas patients are currently prioritised after Tiers A-C, ie after 000 mismatched paediatrics and 000 mismatched HSP/HLA-DR homozygous adults. The lower donor age limit for a kidney/pancreas transplant is currently 8 years of age, but the Pancreas Advisory Group were keen to remove this lower age limit subject to approval from this group. It was agreed that lowering the kidney/pancreas donor age limit would not greatly affect paediatric priority for kidneys (affects approximately one paediatric patient every two years) and the group were happy to endorse that change. However, the increasing number of kidney/pancreas transplants was of concern and it was agreed that the number of paediatric patients missing out on a kidney in Tiers D-E each year because one kidney goes to a kidney/pancreas patient should be monitored on an annual basis, with waiting times borne in mind. **R Johnson**

6.2 It was agreed that the waiting time for diabetic kidney/pancreas, adult kidney and paediatric kidney patients should be compared. It was acknowledged that the numbers would be very small, but still informative. Mrs Johnson will establish if the Pancreas Advisory Group already monitor this. Depending on the results, the Paediatric Sub-group may consider recommending that long waiting paediatric patients should be prioritised above kidney/pancreas patients. **R Johnson**

7 VARIATION IN WAITING TIMES TO TRANSPLANT – KAGPSG(08)4

7.1 Mrs Johnson briefly spoke to this paper which demonstrated variation in waiting times across centres. Dr Milford expressed concerns that Birmingham is accruing an increasingly large paediatric waiting list, impacting on dialysis resources. These are predominantly patients waiting for first transplants, so sensitisation is not an issue, but there is a high proportion of blood group B patients. It was suggested that median waiting time according to ethnicity should be looked at as well as the living donor rate at each centre. Factors such as HLA homozygosity, blood group and age should be taken into account. **R Johnson**

In referring to Table 3.7 of the Kidney Allocation Scheme report, it was noted that 39% of offers of kidneys to paediatric patients were declined. It was agreed that the reasons for declining kidney offers for paediatric patients should be examined, particularly as poorly matched kidneys are no longer offered through the scheme. **R Johnson**

8 SURGICAL CHALLENGES IN PAEDIATRIC TRANSPLANTATION MEETING AT GOSH ON FRIDAY 21 NOVEMBER 2008

8.1 This annual meeting will take place on 21 November 2008. Representation is still required from Birmingham, Cardiff, Liverpool and Southampton paediatric units. Emails to be sent to Dr Marks by 27 October.

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9 ACCESS TO PAEDIATRIC RENAL TRANSPLANTATION – KAGPSG(08)5

9.1 Dr Tizard highlighted the key points from Dr Maxwell's paper on access to paediatric renal transplantation along with possible criteria/guidelines. She also informed the group that paediatric registry data will be sent to the Renal Registry in Bristol this year, enabling an extension to the collaborative work that ODT already undertake with the Renal Registry.

It was proposed that a survey should be designed and sent to all paediatric units via members of the group, determining all paediatric patients currently being worked up for a kidney transplant, whether or not a living donor transplant had been considered for each and the reasons for not proceeding, the protocols used for matching/allocating and avoiding parental antigens, H&I liaison, etc. We will then be able to answer such questions as why patients are not undergoing live donor transplants – is it due to ABO incompatibility and what was the incompatibility? See also para 11.1. **J Tizard/ R Johnson/ A Harmer**

The group discussed what falls under the remit of this group and the BAPN guidelines group and the Clinical Studies Group. This Paediatric Sub-group should be responsible for audits of data to inform decision-making of this and other groups. It was suggested that proposing criteria for matching 'easily matched' patients, intelligent mismatching and blood group incompatibility were within the remit of this group. The guidelines group should deal with matters such as time to work up on the deceased donor list, percentage of dialysed patients listed, etc. The groups should liaise with each other, with Dr Milford as the link. **R Johnson/ A Harmer/ S Fuggle**

The possibility of pooling resources/experience for ABO incompatible transplantation was suggested. Representatives were also reminded that individual patient matchgrade requirements are requested on the patient registration form and that any subsequent changes must be notified to NHSBT ODT. It was suggested that 'easy to match' patients should have a favourable match restriction for up to a year, but not longer.

10 CLINICALLY URGENT SCHEME

10.1 Dr Tizard reported that in addition to all deceased non-heartbeating donor kidneys, approximately 1 in 6 kidneys from deceased heartbeating donors are in fact allocated according to local policy and not through the national allocation scheme. This is because centres may freely allocate a kidney that has been sent to them for a patient who is subsequently found to be unsuitable, provided there are no 000 mismatched patients elsewhere. The Kidney Advisory Group had therefore felt no need to consider a national clinical urgency scheme. There was some doubt about whether paediatric patients were considered when kidneys are reallocated in this way and it was agreed that use of these kidneys in paediatric patients should be investigated. Given the rarity of urgent patients and the complexities involved with establishing a national urgent scheme it was agreed not to take this forward. It was agreed to confirm **R Johnson** **J Tizard**

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with the newly appointed Associate Medical Director for Organ Donation and Transplantation, Professor James Neuberger, whether individual cases can be considered for priority allocation if and when they arise.

11 EVIDENCE OF USE OF NON-HEARTBEATING DONORS IN PAEDIATRICS WITH THE PERCEPTION OF DECREASE IN DECEASED DONOR OFFERS

11.1 Professor Watson raised the issue of non-heartbeating donor kidney transplants in paediatric patients and suggested that each such transplant should be documented. Mr Morgan suggested that these transplants should now be considered for paediatric patients (two have recently been undertaken successfully in Bristol) as results in adult patients are comparable with those of heartbeating donor kidneys. Referring to the latest financial year activity report, Mrs Johnson reported that most adult units are transplanting non-heartbeating donor kidneys, but Nottingham and Belfast paediatric units do not have a linked adult unit with a non-heartbeating donor programme. It was suggested that the question of willingness to accept non-heartbeating donor kidneys for paediatric patients should be added to the survey referred to in para 9.1.

R Johnson

J Tizard

12 ANALYSIS OF PRE-EMPTIVE VERSUS POST-DIALYSIS TRANSPLANTS IN THE UK PAEDIATRIC POPULATION AND ANALYSIS OF TYPES OF TRANSPLANT PRE-EMPTIVE, LRD – EUROPEAN COMPARISON

12.1 Professor Watson had undertaken a local analysis and recommended that an analysis of national data on pre-emptive versus post-dialysis transplant outcome in UK paediatric and adolescent patients is required. This should consider living and deceased donor transplants, adjusting for various risk factors and looking at long-term outcome. There is a possible inter-action effect with age (due to non-compliance) and the groups of most interest are 14-18 and 19-24 years. The feeling is that perhaps pre-dialysis patients may be less adherent with their immunosuppression regimens.

R Johnson

12.2 Dr Tizard reported that an endstage renal failure registry is being established in Europe covering 26 countries. There is wide variation in practice across Europe. Some countries have no pre-emptive patients, some perform just living donor transplants and some perform very few living donor transplants. Dr Tizard is involved in this initiative and the group agreed that UK data could be provided. Outcomes are not required.

J Tizard

13 CUSUM ANALYSES

13.1 Miss Pioli explained the CUSUM charts that are now reported to paediatric units on a six-monthly basis. The group found the presentation useful to aid interpretation of future charts.

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14 IMMUNOSUPPRESIVE REGIMENS – UNIFIED PROTOCOL AND STUDIES

14.1 Dr Marks reported that there is currently no immunosuppression clinical trial being conducted and that it might be an opportune time to make recommendations about a standardised protocol in paediatric patients. It was felt that this was a good idea but that any proposal should go to the research and guidelines groups with any recommendations being reviewed by the Paediatric Sub-group.

15 TRANSITION OF PATIENTS FROM PAEDIATRIC TO ADULT SERVICES (P HARDEN PROJECT)

15.1 An application for data had been received from Paul Harden at Oxford Transplant Centre, to determine the impact of transition from paediatric to adult care on graft function and survival in renal transplant recipients. The National Transplant Database does not hold the date of transfer of patients to adult care, partly because of a flaw whereby paediatric and adult units are not properly distinguished. The group were asked how feasible it would be to provide the dates of transfer so that they could be added to the data held on the National Transplant Database.

The group were very supportive of this important study proposal but could foresee difficulties in to provision of data on transfer dates. However, it was felt that the Paediatric Renal Registry could be a source of this information, or possibly the adult Renal Registry by looking at when patients were first seen by the adult unit. Alternatively, as ODT's Data Collectors could be used, the medical records at the adult units could be reviewed to identify the date the patient was first seen by the adult unit. It was agreed that the data would be more readily available from the mid 1990's rather than the early 1990's.

Dr Tizard and Mrs Johnson will discuss the best way to proceed with Dr Harden. **J Tizard / R Johnson**

16 FOR INFORMATION ONLY:

16.1 Centre-specific wait list and transplant activity – KAGPSG(08)6

16.2 Two-year monitoring report of the 2006 Kidney Allocation Scheme.

17 ANY OTHER BUSINESS

17.1 The question was asked regarding the priority given to patients requiring kidney/liver transplant compared with kidney alone. It was confirmed that the order of precedence is cardiothoracic, liver, pancreas then kidney. Therefore, one kidney would go with the liver automatically if the liver was allocated to a patient also requiring a kidney.

17.2 Professor Watson was surprised at the number of paediatric patients transplanted in adult units, although acknowledged that the number has decreased in recent years. This issue is to be addressed in a document on transition that is being prepared by another group involving both the **D Milford**

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BAPN and the RA, which is led by David Milford.

17.3 As Liverpool's patients are referred to Manchester for transplant, Cardiff patients referred to Bristol and Southampton to either Guy's or Bristol, these patients are not identified separately. It was noted that it would be useful if these could be identified separately for future analyses. Mrs Johnson will determine if this is possible. **R Johnson**

18 DATE OF NEXT MEETING

18.1 The date of the next meeting is Friday 8th May 2009 at 11 am at ODT, Stoke Gifford, Bristol.

NHS Blood and Transplant **October 2008**