

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

**MINUTES OF THE SECOND MEETING OF THE
PAEDIATRIC SUB-GROUP OF THE KIDNEY ADVISORY GROUP
HELD ON THURSDAY, 11 JUNE 2009
IN CONFERENCE SUITE 2, ODT DIRECTORATE, BRISTOL**

PRESENT:	Dr Jane Tizard	Consultant Paediatric Nephrologist, Bristol (Chair)
	Miss Joanne Allen	Senior Statistician, NHSBT
	Mr Marc Clancy	Consultant Transplant Surgeon, Glasgow
	Dr Sue Fuggle	Scientific Advisor, ODT Directorate – NHSBT
	Dr Paul Harden	Consultant Nephrologist, Oxford (part meeting)
	Dr Andrea Harmer	BSHI Representative
	Mrs Rachel Johnson	Principal Statistician, NHSBT
	Dr Brian Judd	Consultant Paediatric Nephrologist, Liverpool
	Dr Stephen Marks	Consultant Paediatric Nephrologist, GOSH
	Mr Shahid Muhammad	Patient/Carer Representative
	Dr Mary O'Connor	Consultant Paediatric Nephrologist, Belfast
	Mr Hany Riad	Consultant Transplant Surgeon, Manchester
	Prof David Talbot	Consultant Transplant Surgeon, Newcastle
	Mr Alun Williams	Consultant Paediatric Urology Surgeon, Nottingham

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

ACTION**APOLOGIES**

Apologies were received from:

Mr Niaz Ahmad, Consultant Transplant Surgeon, Leeds
Mr Francis Calder, Consultant Transplant Surgeon, Guy's Hospital
Dr David Milford, Consultant Paediatric Nephrologist, Birmingham
Dr Rodney Gilbert, Consultant Paediatric Nephrologist, Southampton
Dr Judith van der Voort, Consultant Paediatric Nephrologist, Cardiff

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

1.1 There were no declarations of interest.

**2 MINUTES OF THE PREVIOUS MEETING HELD ON 22 OCTOBER 2008 –
KAGPSG(M)(08)1**

2.1 The minutes of the meeting held on 22 October 2008 were agreed as a correct record.

**3 ACTION POINTS ARISING FROM THE PREVIOUS MEETING –
KAGPSG(AP)(09)1**

3.1 **Item 1 – Kidney allocation scheme:** Analysis work is in hand looking at factors affecting transplant survival, considering weight and height in relation to size matching. This will be reported at a future meeting.

Item 2 – Priority in kidney allocation for paediatric patients turning 18 whilst on the transplant waiting list: Refer to minute 4.1.

Item 3 – Change to lower donor age limit for kidney/pancreas donation:

Refer to minute 7.

Item 4 – Variation in waiting times to transplant: Work is in hand to determine factors affecting waiting time to transplant and will be reported to a future meeting. An analysis of the reasons for declining kidney offers for paediatric patients is reported at minute 6.1

Item 5 – Access to paediatric renal transplantation: Work on designing a survey to determine whether or not a living donor transplant had been considered for all paediatric patients currently being worked up for a kidney transplant has been put on hold. This is due to work taking place in collaboration with the EU registry (ESPN/ERA-EDTA end stage renal failure registry) being established in Europe. A grant for a PhD post in transplantation for a three year period is being applied for and it is hoped that this post will be filled later in the year.

Members discussed whether proposing criteria for matching ‘easily-matched’ patients should be extended to look at the feasibility of intelligent mismatching. Dr Fuggle highlighted that the most appropriate method would be for individual cases to be discussed by the relevant Consultant Nephrologist and the H & I Consultant in the laboratory rather than to develop generic rules which could result in some patients being penalised. It would be possible for details of the frequency of antigens in the donor pool to be prepared and circulated to Centre Directors and the Heads of Laboratories if this would be helpful to centres.

S Fuggle

Item 6 - Clinically urgent scheme: Refer to minute 5.

Item 7 – Evidence of use of non-heartbeating donors in paediatric patients with the perception of a decrease in deceased donor offers: A report on centre specific transplant lists and activity, including data on non-heartbeating donor kidney transplants in paediatric patients, is referred to at minute 13.1 below.

In answer to a query on whether centres would be willing to accept non-heartbeating donor kidneys for paediatric patients it was noted that most centres would accept. Nottingham and Newcastle, however, stated that they would not generally accept these organs for paediatric patients.

Item 8 – Analysis of pre-emptive versus post-dialysis transplants in the UK paediatric population: An analysis of national data on factors affecting transplant survival, considering pre-emptive versus post-dialysis transplant outcome in UK paediatric and adolescent patients is in hand and will be reported to a future meeting.

Item 9 – Transition of patients from paediatric to adult services (P Harden project): Refer to minute 12.

Item 10 – AOB: In Dr Milford’s absence the report on work being undertaken by another group involving both the BAPN and RA on the number of paediatric patients transplanted in adult units, was deferred until the next meeting.

It is not currently possible to separately identify those patients referred for transplant from Liverpool, Cardiff and Southampton. This should be possible once the new registration form, which captures the referring centre details, is available.

4 **UPDATE ON PRIORITY IN KIDNEY ALLOCATION FOR PAEDIATRIC PATIENTS TURNING 18 WHILST ON THE TRANSPLANT LIST**

- 4.1 It was previously agreed by both KAG and the paediatric sub-group, that patients should retain paediatric priority when moving from the paediatric transplant list to the adult transplant list at the age of 18 if they were first actively registered as a child, until such time as they are transplanted or otherwise removed from the list. This change is currently with IT for implementation. Following discussion it was also agreed to exclude donors over 50 for this patient group.

Post meeting note: This change was implemented on 15 July 2009.

5 **CLINICALLY URGENT PATIENTS**

5.1 **Feasibility of priority allocation of kidneys to urgent paediatric patients – KAGPSG(09)2**

- 5.1.1 A proposal for a clinically urgent scheme for paediatric patients in whom dialysis access was running out was agreed at the Kidney Advisory Group meeting in May. Dr Tizard was given responsibility for developing a protocol to specify the procedure to be followed and to identify those involved in the decision-making process on behalf of the KAG paediatric sub-group.

Any decisions would be advised to the centre concerned which, in turn, would be responsible for advising ODT to ensure the patient is listed. There would be no requirement for KAG to endorse the prioritisation of individual patients under this proposal.

5.2 **Reallocation of kidneys through centre choice – KAGPSG(09)3**

- 5.2.1 Currently there are several rules that apply to kidneys that have been accepted by a centre for a named patient who subsequently cannot receive the transplant. If the kidney has already been dispatched and there are no patients nationally in Tiers A to D or 20 hours of cold ischaemia time have passed, the centre can use the kidney in the most appropriate patient from their local list. In the absence of a clinically urgent scheme for kidney patients, concern had been expressed as to whether paediatric patients are considered when kidneys are allocated in this way. In the first three years of the 2006 National Kidney Allocation Scheme (2006 NKAS) for deceased heartbeating donor kidneys all 413 of the kidneys used in alternative patients of the centre's choice were transplanted in adult patients. Members noted that if a matching run of the local list was performed to help inform centre's choice, paediatric patients would not appear for donors aged over 50 years of age. However, of the 413 donors, 50% were aged 50 years or younger and paediatric patients would therefore appear on the local list for such a matching run.

Members were asked to consider ways in which paediatric patients can be considered for kidneys reallocated through centre choice. Following discussion about the difficulty of checking which paediatric patients would have missed out on these offers it was agreed that Dr Tizard would write to all UK renal centres providing paediatric renal transplantation and related laboratories requesting that consideration be given to paediatric patients when kidneys are reallocated through centre choice.

J Tizard

6 REASONS FOR DECLINE OF KIDNEY OFFERS FOR PAEDIATRIC PATIENTS – KAGPSG(09)4

- 6.1 A paper was received reporting the reasons for the decline of kidney offers for paediatric patients since the introduction of the 2006 NKAS. Forty eight percent of offers made for paediatric patients were declined in the first three years of the scheme with the majority of offers declined at each centre for donor reasons, these being past history or size in the majority of cases. Members considered the information submitted and commented on the variations between centres in the number of declined offers. Miss Allen agreed to review the detail submitted by centres on past history, size, virology, and age, to enable consideration of guidelines on declining offers for these reasons. Miss Allen also agreed to provide representatives from Belfast with a breakdown of the reasons given for decline of kidney offers declined for 'centre' reasons at that centre. It was also agreed that a new reason for decline should be available on the Duty Office picklist to record that a kidney offer has been declined because a live donor is lined up.

J Allen

J Allen

J Allen

7 SIMULTANEOUS PANCREAS/KIDNEY TRANSPLANTATION

7.1 Waiting time comparison: kidney/pancreas and kidney-only patients – KAGPSG(09)5

- 7.1.1 Patients awaiting a simultaneous pancreas/kidney (SPK) transplant currently receive priority over patients awaiting a kidney-only (KO) transplant in Tiers D and E. Concerns have been expressed about increased waiting times to kidney transplant for paediatric patients and a paper comparing the median waiting time of patients recently registered for their first KO or SPK transplant was received for consideration. It was noted that there was no statistically significant difference in waiting times between paediatric patients awaiting a KO transplant with adults awaiting a SPK transplant. This was further discussed at minute 7.2 below.

7.2 Assessing missed offers for paediatric patients in Tier D – KAGPSG(09)6

- 7.2.1 At the May 2009 Kidney Advisory Group meeting the impact of simultaneous pancreas/kidney transplantation (SPK) on kidney-only (KO) patients in Tiers D and E was discussed. It was suggested that there may be a general problem of paediatric and adult weighting in Tier D and further work has been carried out to identify the types of patient who received the KO transplant where the other kidney was transplanted in a SPK patient.

Although 44 kidney offers for paediatric patients in Tier D were missed in the first 3 years of the scheme because one kidney was transplanted with the pancreas, the other kidney recipient was a different paediatric patient on 21 occasions, and on one occasion a 20 year-old patient who was first registered as a paediatric patient. On 3 occasions no kidneys were available for KO patients as the kidney was transplanted with the heart or liver. On 8 occasions 000 mismatched adults in Tier C received a transplant, leaving no kidneys available for offering in Tier D. On the remaining 11 occasions 000 mismatched adults in Tier D ranked higher than the favourably matched paediatric patients and therefore received a transplant.

Members discussed whether all paediatric patients should be prioritised above SPK patients for Tier D offers, especially if matchability is taken into account. Mrs Johnson highlighted that this would mean that both adult and paediatric patients would be prioritised above SPK patients and this could

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potentially have a significant impact on the SPK programme. The group needs to find a way of addressing the problem of paediatric patients not having priority in Tier D without affecting the SPK patients and this would need to be evidenced in order to build a case for a change in priorities. Mrs Johnson, Dr Fuggle and Miss Allen would look into this issue and a proposal would be submitted to KAG for consideration.

**R Johnson/
J Allen/
S Fuggle**

Mrs Johnson raised the separate issue of prioritising Tier D long waiters and added that it would be possible to adjust the system to remedy this situation very simply with endorsement from KAG.

***Post meeting note:** The same additional points awarded to long-waiting paediatric patients in Tier E has been applied to long-waiting paediatric patients in Tier D since 15 July 2009 (ie 2500 points for paediatric patients waiting between 2 and 3 years and 5000 points for paediatric patients waiting more than 3 years).*

8 IMPACT OF CHANGE TO 2006 KIDNEY ALLOCATION SCHEME ON LONG-WAITING PAEDIATRIC PATIENTS – KAGPSG(09)7

- 8.1 In April 2008 long-waiting paediatric patients began to receive additional points when prioritised within Tier E of the 2006 kidney allocation scheme. A paper was received detailing the impact of this change in increasing the number of transplants performed for this group of patients. In the third year of the 2006 NKAS (when this change was applied) there was an increase in the proportion of patients achieving rank 1 or 2 on at least one occasion and an increase in the transplant rate. Of the seven long waiting paediatric patients still actively waiting, five have a calculated reaction frequency (cRF) of 97 – 100%, one has a 71% cRF and the remaining patient has a 0% cRF but also has a special instruction not to receive offers of kidneys from donors over 45kgs in weight.

Following discussion it was agreed that centres should review the special instructions currently in place for these patients and make a decision on whether these should be removed. It was noted that waiting list reports showing the cRF for each patient are available through H & I laboratories and these are updated monthly.

**Centre
Reps.**

9 THE USE OF NON-FAVOURABLY MATCHED GRAFTS IN PAEDIATRIC PATIENTS – KAGPSG(09)8

- 9.1 A report showing the use of non-favourably matched grafts in paediatric patients was received for information. As from June 2003 any non-favourably matched kidney-only transplants in a child with a matchability score of five or less is followed up with a letter enquiring about the circumstances surrounding the transplant, with annual reports of cases being provided to KAG. It was noted that as from 1 April 2008 when paediatric patients with a waiting time of more than two years were prioritised when they appeared in Tier E of the kidney matching run, there had been a number of non-favourably matched grafts in 'easy to match' paediatric patients. Five such transplants were reported at the autumn 2008 meeting of the Kidney Advisory Group and a further two have occurred since then. However, Dr Tizard added that no centres were outwith the current guidelines (which only apply to the first year on the active list) and therefore these incidences were not investigated.

10 CONSENT FOR EBV MISMATCH

- 10.1 Dr Tizard reported that the possibility of screening all donors for EBV is currently being raised with the Advisory Committee on the Safety of Blood, Tissues and Organs (SaBTO). The main issue with this proposal is securing funding for a screening service.

In a related issue, members were advised of a situation where a paediatric patient developed post-transplant lymphoproliferative disease (PTLD) due to lack of information on EBV status of the live donor. It was noted that DTCs have reported that funding for the test as part of live donor work-up is of particular concern. Dr Tizard queried whether centres should be formally consenting patients for an EBV mismatch.

11 SCHOOLING AND EDUCATION IN PAEDIATRIC RENAL PATIENTS – KAGPSG(09)9

- 11.1 An article for the Journal of Child Health Care on hospital school liaison for children with renal transplants was received for discussion. The article explores collaboration between health and education staff as a key aspect of educational provision for children with chronic medical conditions. Following discussion members felt that it would be useful for this to be considered by the BAPN Executive and, in particular, the workforce planning group.

J Tizard

Additionally members noted the results of a PhD on transplant recipients carried out by Mrs Helen Lewis, former patient representative on KAG. Patients were categorised into those who developed end stage renal failure before the age of 16 and those who developed it after the age of 16, looking at the differences in various aspects of their life. Those who developed end stage renal failure before the age of 16 were found to be disadvantaged in a variety of areas including employment and housing.

12 TRANSITION OF PATIENTS FROM PAEDIATRIC TO ADULT SERVICES – KAGPSG(09)10

- 12.1 Dr Harden joined the meeting to discuss a study on the impact of transition from paediatric to adult care on graft function and survival in renal transplant recipients. The study highlighted the poor communication between adult and paediatric centres with no co-ordinated pathway resulting in a lack of trust by the patient due to a loss of continuity between centres. Additionally there appears to be little or no peer support in many adult centres. Thirty percent of patients on the study either lost their graft or experienced reduced function on transition from a paediatric to an adult centre, highlighting the need to focus on the issue of non-adherence. There is a need for clinicians from both centres to meet with these patients around the age of 14 to make a joint decision on when the transfer will take place.

The study is now being broadened to look at models of transition including the development of a young adult clinic for those who present first at between the ages of 16 and 20.

Members discussed the issue of recording the time of transition as not all centres complete this data on the form returns. It is possible that this information could be made available via the Renal Registry. It is unlikely that this type of data will be held for the past 20 years and it may be that specific records will need to be sourced to identify and record the transition data. Members considered what might be the best approach to obtain this data,

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either an approach to individual centres or a search of the registry. Mrs Johnson added that ODT use data collection teams to collect forms from centres, which could possibly be used for the study, although there would be a cost involved for this service. It was felt that a protocol should be written specifying the data that needs to be collected. Discussion could then take place to assess what data can be collected via the registry, which could then be matched to ODT data. Dr Harden agreed to meet with Dr Carol Inward, Mrs Johnson, Dr Tizard and a representative from the adult Renal Registry to take this forward.

**P Harden/
R Johnson/
J Tizard**

Dr Tizard raised the issue of consent for the use of patients' records and would be discussing this with Dr Inward in terms of the registry.

It was suggested that, going forward, the date of transfer could be added to the relevant data collection forms.

**R Johnson/
J Allen**

13 FOR INFORMATION ONLY**13.1 Centre-specific wait list and transplant activity – KAGPSG(09)11**

13.1.1 Members noted a paper on centre-specific wait list and transplant activity between 2000 and 2008.

13.2 Three year review of deceased donor kidney allocation scheme – KAGPSG(09)12

13.2.1 A report on the first three years (April 2006 to March 2009) of the 2006 NKAS was received for information.

14 ANY OTHER BUSINESS

14.1 There were no further items of business.

15 DATE OF NEXT MEETING

15.1 The next meeting is scheduled for Tuesday, 24 November 2009 in room CS1 at ODT, Bristol (time to be confirmed). Dr Tizard asked members to ensure that each centre is represented at the next meeting.