

UK TRANSPLANT

**MINUTES OF THE THIRTEENTH MEETING OF THE
KIDNEY ADVISORY GROUP
HELD ON WEDNESDAY, 11 JUNE 2008
IN CONFERENCE SUITE 2, UK TRANSPLANT, BRISTOL**

PRESENT:	Professor Andrew Bradley Mr Niaz Ahmad Mr Argiris Asderakis Ms Lisa Burnapp Miss Laura Buist Professor Dave Collett Professor Phil Dyer Miss Sue Falvey Dr Sue Fuggle Dr Robert Higgins Mrs Christine Jansen Mrs Rachel Johnson Mrs Helen Lewis Mr Justin Morgan Dr Martin J Raftery Mr Chris Rudge Mr Badri Shrestha Mr Alex Stephen Dr Jane Tizard Dr Anthony Warrens Mr Chris Watson	Chairman Representative for Newcastle & Leeds Deputy for Dr Richard Moore, Representative for Wales Living Donor Scheme Representative Representative for Scotland Director of Statistics & Audit, UKT BSHI Representative Director of Donor Care & Co-ordination, UKT Scientific Advisor, UKT Representative for Cambridge, Birmingham & Coventry Donor Transplant Co-ordinator Representative Principal Statistician, UKT Patients' Forum Representative Representative for Oxford, Bristol, Plymouth & Portsmouth Representative for North Thames Managing & Transplant Director, UKT (<i>part mtg</i>) Representative for Trent Patients' Forum Representative BAPN Representative BTS Representative Chairman, Pancreas Advisory Group
In Attendance:	Mrs Kathy Cardwell Mr Iain Harrison Miss Lisa Mumford	Secretary, Corporate Services, UKT IT Directorate, UKT Statistician, UKT

ACTION**APOLOGIES**

Apologies were received from Mr John Connolly, Mr Abdul Hammad, Mr Geoff Koffman, Ms Dawn McPake, Dr Philip Mason, Dr Richard Moore and Ms Triona Norman.

- 1 DECLARATIONS OF INTEREST IN RELATION TO THE AGENDA –
KAG(08)1**
- 1.1 There were no declarations of interest.
- 2 MINUTES OF THE MEETING HELD ON 5 DECEMBER 2007 –
KAG(M)(07)2**
- 2.1 The minutes of the previous meeting were accepted as a true and correct record.

ACTION

2.2 **Action points – KAG(AP)(08)1**

2.2.1 **Item 1 – Change to lower donor age limit for kidney/pancreas donation:** This item is ongoing awaiting a recommendation from the paediatric sub-group of KAG.

J Tizard

Item 2 – Council of Europe review of the use of organs from donors with tumours: This item is in hand as the data is still being worked on.

Item 3 – 18-month monitoring and report back from the Kidney Allocation Review Group meeting on 19 November 2007: Refer to minute 7.3.

Item 4 – Analysis of patients joining the National Kidney Transplant List: This item is in hand and will be reported to the next meeting.

R Johnson

Item 5 – Establishment of a paediatric sub-group: Refer to minute 6.3.

Item 6 – Renal transplantation in highly sensitised patients using left lateral lobe of liver with kidney transplant: An update was received from Mr Koffman in his absence advising that no transplants had yet been performed on the pilot study. Ethics approval has been obtained and information leaflets produced for patients. A shortlist of suitable patients has been drawn up and it is anticipated the programme will start within the next couple of months. At this stage King's is the only centre involved in the pilot study. As Mr Stapleton, Duty Office Manager, had now left UKT Miss Falvey & Dr Fuggle agreed to liaise with Mr Koffman to clarify the allocation protocol for this procedure.

S Falvey/
S Fuggle/
G Koffman2.3 **Matters arising not separately identified**

2.3.1 There were no further matters arising.

3 **MANAGING & TRANSPLANT DIRECTOR'S REPORT**3.1 **Update on Organ Donation Taskforce**

3.1.1 Mr Rudge reported that progress on implementation of the Taskforce recommendations is underway and this will be overseen by a Programme Delivery Board to be chaired by Professor Sir Bruce Keogh, NHS Medical Director. The recommendations will have a significant impact on NHSBT and the establishment of a national organ donor organisation has occurred simultaneously with changes within NBS. NHSBT is therefore in the process of changing its structure and a new division of Organ Donation and Transplantation within NHSBT will take on the work of UKT. Additional work will include the employment of co-ordinators by NHSBT and recruitment to at least double the existing number of co-ordinators, commissioning of retrieval teams, and the promotion of donation within critical care.

Mr Rudge will be joining the Department of Health on secondment as National Clinical Director for Transplantation to lead the day-to-day implementation work. A new Board level director will be appointed for the new Organ Donation and Transplantation division with additional clinical input from an Associate Medical Director which will be a post for approximately 4 days per week. In addition, two clinical roles are to be created, one for commissioning retrieval over the next few years and the second for a critical care clinician to work on the relationship between donation and critical care units. The interviews planned for the three clinical advisor roles to work on issues driven through the renal, liver and

cardiothoracic advisory groups have now been postponed in light of the changes to the NHSBT structure. These will be reinstated following confirmation of the arrangements for the role of Associate Medical Director.

3.2 **Commissioning of renal transplant services – KAG(08)2**

- 3.2.1 Previous KAG meetings have discussed the desirability of a national commissioning framework for renal transplant services and the Organ Donation Taskforce report also recommends that consideration be given to this. Initial discussions with NCG had suggested that although renal transplantation is likely to fall outside their remit it may be possible to consider alternative arrangements. Mr Rudge asked members of KAG to discuss this issue and it was agreed that a paper outlining the current situation and its disadvantages, together with the advantages of a more integrated national commissioning framework should be sent to Mr Rudge for consideration by NCG.

**A Bradley/
C Rudge**

3.3 **H & I Services for Transplantation – KAG(08)3**

- 3.3.1 NCG had received an approach suggesting that they commission H & I services on a national basis as opposed to the current arrangement whereby laboratories are established and funded in a variety of ways. NCG had requested the advice of UKT and Mr Rudge asked KAG to support a proposal whereby a paper is submitted to NCG setting out the current situation of H & I services for organ transplantation, identifying some of the difficulties and inadequacies that result from the current situation, and in particular outlining the clinical consequences of these difficulties. This could also include options for possible future arrangements and should emphasise the potential cost-savings of renal transplantation when compared with the costs of long-term maintenance dialysis.

Members discussed this proposal and wholeheartedly supported the suggestion as H & I services are critical to achieving the anticipated increase in the number of organ transplants arising from the Taskforce recommendations. It was agreed that Dr Fuggle and Professor Dyer should provide key points for Professor Bradley to draft a proposal in liaison with Mr Rudge for submission to NCG. It was noted that this should be a nationwide UK service and NSD in Scotland may need to be consulted in addition to NCG.

**S Fuggle/
P Dyer/
A Bradley/
C Rudge**

4 **SCIENTIFIC ADVISOR'S REPORT**

4.1 **HLA Donor discrepancy follow-up 2007 – KAG(08)4**

- 4.4.1 Dr Fuggle spoke to a paper on the HLA donor discrepancy follow up scheme for 2007. The results of monitoring show that the level of discrepant donor HLA types reported to UKT remains at a very low level. All discrepancy reports are circulated to laboratories in real time and reported to the UKT Clinical Governance Monitoring Group quarterly. Professor Dyer suggested that this report should be written up into a paper for publication as there is now ten years worth of data for scrutiny.

4.2 **Minimum resolution for reporting donor and recipient HLA types – KAG(08)5**

- 4.2.1 A report showing the improvement in compliance with the repertoire by centre was received. Compliance for recipient HLA types has increased from 86% to 93%, for living donor types from 80% to 93% and for deceased donor types from 94% to 97%. It was noted that one laboratory is not achieving compliance routinely for recipients or for live donors. Dr Fuggle is in dialogue with this laboratory in order to achieve compliance in the future. It was recommended and agreed that this paper should be circulated and produced for the next meeting of KAG and then submitted annually thereafter.

S Fuggle

4.3 **Definition of highly sensitised patients – KAG(08)6**

- 4.3.1 Currently a patient is classified as highly sensitised from HLA antibody reaction frequency data supplied to UK Transplant by the H & I laboratory. In light of significant changes in antibody screening and specification technology Dr Fuggle submitted a paper proposing a method of defining highly sensitised patients based on a calculated reaction frequency derived at UKT from unacceptable HLA antigens listed by the laboratory. Calculated reaction frequency is used in the paired/pooled living donor and the sharing scheme for sensitised pancreas patients and could be introduced for deceased donor kidney allocation.

Members were asked to consider whether a calculated sensitisation level, based on all unacceptable specificities reported, should replace the reported reaction frequency in the classification of highly sensitised patients in the 2006 National Kidney Allocation Scheme for deceased donor kidneys. It was noted that the results from calculations show that a significant proportion of patients on the adult and paediatric transplant list have a higher calculated than reported reaction frequency. In 9% of cases the patient's reported reaction frequency is <85% but when calculated is $\geq 85\%$, leading to a classification of HSP.

Members were happy to endorse this proposal although it was accepted that this could not be implemented immediately due to the time required for user testing. UKT would take this forward and report progress at the next meeting of KAG.

**R Johnson/
S Fuggle**

4.4 **Forum articles for 'Transplantation' – KAG(08)7**

- 4.4.1 Members noted that the editors of 'Transplantation' have accepted a proposal from UK Transplant to publish a series of papers as a Forum entitled 'Kidney Allocation in the UK: Past, Present and Future'. The articles will be based on the analyses performed for the work of the Allocation Task Force. Mrs Lewis asked that the commentary for the papers contained details of the rationale for giving priority to younger adults. It was noted that there would also be some commentary on the rationale of the work on equity of access which formed part of the original work.

5 DIRECTOR OF STATISTICS AND AUDIT'S REPORT

5.1 Conference presentations, current and future work – KAG(08)8

5.1.1 A paper summarising the work of the UKT Statistics & Audit Directorate in relation to kidney transplantation was noted. Professor Collett highlighted projects currently taking place including:

- Quarterly CUSUM analyses
- Monitoring of the 2006 Kidney Allocation Scheme
- Data collection & organ matching/allocation for both altruistic and paired donation and facilitation of pooled donation
- Analyses of the database on the incidence of malignancy in recipients of kidneys, liver and cardiothoracic organs
- Updating centre specific data on the UKT website
- A review of outcomes after non-heartbeating donor kidney transplantation

5.2 Report from the Kidney & Pancreas Research Group – KAG(08)9

5.2.1 An update report was received on the work of the Kidney and Pancreas Research Group. Requests from clinical staff for data for research purposes had been considered and five projects agreed. A further seven proposals were declined due to lack of sufficient data and overlap with current UKT work.

In addition, an application was made to NHSBT for funding to support a wide ranging study on donation and outcomes after cardiac death. This three-year study is to be funded in full and will involve recruiting a medically qualified research fellow to be based at Addenbrooke's.

6 KIDNEY ALLOCATION SCHEME

6.1 Two year report for Kidney Allocation Scheme – KAG(08)10

6.1.1 Mrs Johnson presented a report on the two year review of the 2006 Kidney Allocation Scheme which was introduced in April 2006. Comparisons were made with data from 2005 and the following key points were noted:

- Improvements in HLA mismatch, including well matched grafts for young patients.
- More long waiting patients have been transplanted (28% of transplants now in patients waiting >5 years).
- Fewer transplants in O and B patients as a result of fewer O and B donors than previously.
- Some improvement in access to transplant for ethnic minority patients
- The excess of HLA-B and DR homozygous patients on the transplant list has almost been eliminated.
- Increase in the number of difficult to match patients transplanted
- Median waiting time to transplant for paediatric patients has remained unchanged (10 months).
- Improved access to transplant for young adult patients.
- Median cold ischaemic time has fallen (not necessarily as a result of the scheme).
- No difference in either graft or patient survival (unadjusted) for adult or paediatric patients when comparing outcomes of transplants in

2005 with the year from April 2006.

Dr Tizard highlighted that the total number of offers to paediatric patients had decreased. Mrs Lewis asked if the paediatric and adult data could be merged and split into age groups to make it easier to scrutinise the data. Mrs Johnson agreed to consider whether this is achievable.

R Johnson

As the scheme has now been in operation for two years it was suggested that a review should take place of the number of sensitised patients on the transplant list and specifically whether the number of patients sensitised to HLA-A has changed.

**S Fuggle/
R Johnson**

Mrs Lewis requested the inclusion on the website of information on the prioritisation of younger adults in the scheme which is leading to improved access to transplant for this group of patients. Mr Stephen highlighted that improved access for patients aged >60 should be a priority and expressed his concern that the allocation scheme may not be achieving this.

D Collett

6.2 **Future monitoring arrangements**

6.2.1 It was agreed at the November 2007 meeting of the Kidney Allocation Review Group (KARG) that the current safeguards should be retained for a further six months, and then reduced with a view to phasing them out completely in 18 months' time. Changes to the Kidney Allocation Scheme therefore took place in April 2008 and will continue in April 2009 and Professor Bradley proposed that in light of this, future meetings of KARG would not be necessary. It was agreed that the monitoring of the scheme would now be the responsibility of the Kidney Advisory Group where all centres are represented. Professor Bradley would write to Directors of all Renal Centres to confirm this arrangement.

A Bradley

6.3 **Establishment of a paediatric sub-group – KAG(08)11**

6.3.1 Dr Tizard updated members on the arrangements for a paediatric sub-group of KAG. It was planned that the sub-group would meet annually with the first meeting on 22 October 2008 and thereafter members would correspond via e-mail. A membership list for the sub-group was received for information and the need for a patient representative (carer) on the group was highlighted. Dr Tizard agreed to work to identify a carer representative.

J Tizard

6.4 **Transfer of paediatric patients to adult list – KAG(08)12**

6.4.1 A proposal was received on equity of access for paediatric patients in the transitional period when moving from the paediatric transplant list to the adult transplant list at the age of 18. In light of the relatively small number of patients involved it was suggested that consideration be given to a patient retaining paediatric priority, if they were first registered as a child, until such time as they are transplanted. Following discussion it was agreed that this proposal should be endorsed and reviewed by the paediatric sub-group.

J Tizard

7 CMV matching – KAG(08)21

- 7.1 A paper from Mr Hammad was tabled on his behalf proposing a review of the possibilities of CMV matching in light of the fact that CMV disease continues to be a major cause of morbidity in kidney transplant patients. There was concern over whether a change such as this would distort the Kidney Allocation Scheme as well as whether this would disadvantage paediatric patients. Members also questioned the quality and accuracy of typing for CMV. Ms Burnapp highlighted the need to consider how this issue would affect live donors as well as deceased donors.

Although it was recognised that matching for CMV is a problem it was agreed that no change should be made to the allocation system until further analysis of the influence of CMV on patient and graft survival can be undertaken by Mrs Johnson. Professor Bradley would reply to Mr Hammad advising of the group's decision.

R Johnson
A Bradley

Dr Tizard advised members of a study at Great Ormond Street Hospital using EBV vaccine and asked if it would be possible to obtain EBV data on a national basis. EBV status is currently only reported for pancreata and not for kidneys although the new kidney registration form does request this information. It was noted that donors are not always tested for EBV so all recipient centres would have to be asked to EBV type the donor from serum. This would not need to be reported as a matter of urgency and therefore would not need to be completed out of hours. Miss Falvey and Dr Warrens agreed to follow up on how and when this data could best be collected.

S Falvey/
A Warrens

8 MINUTES OF THE PANCREAS ADVISORY GROUP – KAG(08)13

- 8.1 Mr Watson updated the meeting on the key points from the recent Pancreas Advisory Group including the establishment of a working party to develop a national sharing scheme for both whole organ transplants and islets.

A total of 247 pancreas transplants were performed in 2007/08, including 37 non-heartbeating donor transplants. As at 1 April 2008 there were 217 patients actively registered for a transplant, 61 of whom had a calculated reaction frequency of $\geq 30\%$.

An analysis of the use of different induction agents had indicated that increased use of CD52 may partially explain some of the improvement in short term pancreas transplant survival seen in recent years. However, there was insufficient evidence at this stage to be confident of this conclusion.

9 UPDATE ON PAIRED AND ALTRUISTIC DONATION – KAG(08)14

- 9.1 A summary of altruistic and paired/pooled donation activity was received. To date eight altruistic and six paired donor transplants have taken place. The latest pooled donor matching run identified 16 possible transplants although it is likely that 11 of these transplants will not proceed as a result of positive cross-matches. The details of these are being investigated by Dr Fuggle.

Disappointment was expressed at the lack of progress on the paired/pooled scheme and members agreed that the next run on 1 July 2008 should proceed as planned with priority being given to 2-way exchanges (although 3-way exchanges would also be considered) given the current lack of success and the need to manage patients' expectations when they enter the scheme. It was suggested that both donors and recipients should be DP typed for both the paired/pooled and altruistic schemes. Dr Fuggle is currently facilitating a discussion for the Cardiothoracic Advisory Group (CTAG) on allocating organs to sensitised patients and agreed to consider the implications for KAG. An update report will be submitted to the next meeting.

S Fuggle

10 ALLOCATION OF EXTENDED CRITERIA FOR KIDNEYS FOR DUAL TRANSPLANTS – KAG(08)15

- 10.1 A paper was received from Mr Ahmad proposing the use of dual grafts using agreed criteria for allocation. Concern was expressed over introducing arbitrary criteria for this process and it was felt that defined criteria would need to be developed for this process. Following discussion it was agreed that analysis of the national database should be carried out to inform future discussion.

R Johnson

11 COMPARING ONE YEAR RENAL FUNCTION ACROSS TRANSPLANT CENTRES – KAG(08)16

- 11.1 A paper on a comparison across centres of renal function at 12-months post transplant from both heartbeating and non-heartbeating donor kidney only transplants was received for discussion. Preliminary analysis showed that for two centres the average eGFR at 12-months post-transplant is significantly higher than the national average whilst for another two centres the average eGFR at 12-months post-transplant is significantly lower than the national average. Further work is needed to determine if this method is a suitable way of comparing outcome across centres. This includes contacting all UK kidney transplant centres to determine the method of serum creatinine measurement that is being used and whether a correction factor has been applied. Members also discussed other options for collecting accurate eGFR data from centres or laboratories. Once further investigations are complete it is hoped to incorporate the results in to the centre-specific reports on the UKT website.

12 DEPARTMENT OF HEALTH SPONSOR ROLE FOR HEALTH BUILDING NOTE ON RENAL CARE TRANSPLANT UNITS

- 12.1 Papers for this item were previously circulated for information. Members were asked to forward any comments on the document to Triona Norman, Transplantation Lead at the Department of Health (Triona.norman@dh.gsi.gov.uk).

13 NON-COMPLIANCE REPORT

- 13.1 There were no instances of non-compliance to report.

14 FOR INFORMATION ONLY

14.1 Transplant activity report: April 2008 – KAG(08)17

14.1.1 Members noted for information the transplant activity report as at April 2008.

14.2 Minutes of the Renal Transplant Services Meeting on 17 March 2008 – KAG(08)18

14.2.1 The minutes of the Renal Transplant Services meeting held earlier this year were tabled for information.

14.3 Reasons for non-retrieval and non-use of kidneys – KAG(08)19

14.3.1 A paper summarising the reasons for non-retrieval and non-use of kidneys from deceased solid organ donors in 2007 was received and noted.

14.4 Use of non-favourably matched grafts in paediatric patients – KAG(08)20

14.4.1 Members noted a paper on the use of non-favourably matched grafts in paediatric patients which is reported to KAG annually. One case, which took place in May 2008, was reported.

15 ANY OTHER BUSINESS

15.1 Professor Dyer announced that he would be standing down as BSHI representative on KAG and that BSHI would advise of a replacement in due course.

15.2 Ms Jansen also announced that she would be stepping down as the donor co-ordinator representative on KAG. The UK Transplant Co-ordinators Association (UKTCA) would advise of a replacement representative prior to the next meeting.

15.3 As part of its overall restructuring, NHSBT is reviewing the advisory group structure and processes. It was noted that this is unlikely to change significantly the way in which advisory groups currently operate.

16 DATE OF NEXT MEETING

16.1 The next meeting is scheduled for Wednesday 26 November 2008 at UK Transplant, Bristol.

UK Transplant

June 2008

Circulation:

Members	UKT Donor Transplant Co-ordinator	Regional Managers
Directors of Renal Transplant Units	UKT Briefing Group	
Directors of Renal Paediatric Transplant Units	Members of UKT Patients' Forum	
Heads of H & I Laboratories	UKTCA	