

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

**MINUTES OF THE NINETEENTH MEETING OF THE  
KIDNEY ADVISORY GROUP HELD AT 12.30 PM ON WEDNESDAY,  
25 MAY 2011 AT THE SOCIETY OF CHEMICAL INDUSTRY, LONDON**

**PRESENT:**

Prof. Andrew Bradley	Chairman
Mr Niaz Ahmad	Representative for Newcastle & Leeds (part meeting)
Ms Lisa Burnapp	Lead Nurse for Living Donation
Mr John Connolly	Representative for Northern Ireland
Ms Karen Morgan	SNOD representative
Prof Peter Friend	Chairman, Pancreas Advisory Group
Dr Susan Fuggle	Scientific Advisor, ODT
Dr Sian Griffin	Deputy for Dr Richard Moore, Representative for Wales
Mr Abdul Hammad	Representative for Manchester & Liverpool
Dr Susan Martin	Deputy for Dr Andrea Harmer BSHI representative
Dr Robert Higgins	Representative for Cambridge, Birmingham & Coventry
Mr Alex Hudson	Statistics & Clinical Audit, NHSBT
Mrs Rachel Johnson	Statistics & Clinical Audit, NHSBT
Miss Lorna Marson	Representative for Scotland
Mr David Mayer	Clinical Lead for Organ Retrieval, NHSBT
Dr Philip Mason	Renal Association/Registry representative
Mr Justin Morgan	Representative for Oxford, Bristol, Plymouth & Portsmouth
Prof. James Neuberger	Associate Medical Director, ODT
Dr Martin Raftery	Representative for North Thames
Mr Badri Shrestha	Representative for Trent
Dr Jane Tizard	BAPN representative
Prof Anthony Warrens	BTS representative
Mrs Ann Yates	Duty Office Manager, ODT

**In attendance:** Mrs Kathy Zalewska      Corporate Services, ODT – Secretary

**ACTION****APOLOGIES**

Apologies were received from Miss Sue Falvey, Dr Andrea Harmer, Mr Iain Harrison, Mr Geoff Koffman, Dr Richard Moore, and Mr Chris Rudge

- 1        DECLARATIONS OF INTEREST IN RELATION TO THE AGENDA –  
KAG(11)1**
- 1.1        There were no declarations of interest in relation to the agenda.
- 2        MINUTES OF THE MEETING HELD ON 7 DECEMBER 2010 –  
KAG(M)(10)2**
- 2.1        The minutes of the previous meeting were agreed as a correct record.

2.2 **Action points – KAG(AP)(11)1**

2.2.1 **Item 1 – Reimbursement of paired/pooled and non-directed altruistic living kidney donors:** Ms Burnapp reported that Commissioners are planning to put together a national pathway for living donor expenses which will start to be developed next month. This should encompass all aspects of living donor reimbursement. Ms Burnapp will report on progress at the next meeting of KAG.

L Burnapp

**Item 2 – Organogram of advisory and clinical groups:** Work on a flow diagram is in hand. This will be circulated to advisory groups in due course.

**Item 3 – Report from the DCD Kidney Allocation Working Party held on 27 September 2010:** The issue of obtaining donor HLA typing prior to procurement has been raised with NSCT.

**Item 4 – Reallocation of DBD donor kidneys:** A further report will be submitted to the Autumn 2011 meeting of KAG.

A Hudson

**Item 5 – Offering of DCD donor kidneys:** Work is ongoing to find a resolution to the lack of definition within the Duty Office SOP for when a pair of DCD donor kidneys should be offered for a single recipient.

A Bradley

**Item 6 – Dual kidney transplants:** Refer to minute 9.2.

**Item 7 – Biopsy of donor kidneys:** Refer to minute 11.

2.3 **Matters arising, not separately identified**

2.3.1 There were no further matters arising.

3 **ASSOCIATE MEDICAL DIRECTOR'S REPORT**3.1 **Developments in NHSBT**

3.1.1 Prof Neuberger reported on the following developments:

- The vast majority of CLODs are now in place and work is taking place on forming regional collaboratives. It is planned that CLODs will play a much more active role in raising issues within their trusts.
- Dr Gerlinde Mandersloot has been appointed to the role of Clinical Lead for Donor Optimisation working with intensive care clinicians to develop policies to maximise donor care and develop a consistent approach to managing donors.
- Prof Rutger Ploeg has been appointed as Principal Investigator to work for one day a week heading up a programme of research with the broad aim of increasing the number and quality of organs for transplantation. A meeting is planned for the autumn to try to launch a strategy to gain feedback from clinicians.
- There are still a number of concerns around the value of EOS. An external review of the process has taken place looking at how to make it fit for purpose.

- Research monies have been made available to appoint a research fellow to look at donor transmitted cancers. Centres were asked to nominate someone within their centres with whom this person could liaise. The aim is to develop a much greater understanding of the situation in order to help surgeons to decide on the risks of accepting organs from donors who may have cancer or have had cancer in the past.

### 3.2 **Governance issues**

#### 3.2.1 **Development of selection and allocation policies – KAG(11)2**

The NHSBT patient selection and organ allocation policies have undergone a legal review for compliance purposes. A single policy for selection and allocation is being developed, containing separate sections for individual organ groups. Sections will be regularly reviewed by the relevant Advisory Group and any changes implemented twice a year on 1<sup>st</sup> June and 1<sup>st</sup> December.

Dr Tizard highlighted that the definition of a child in the allocation of kidneys should be up to the age of 18 years and not 16 years as indicated in the introductory section. Prof Bradley agreed to circulate the kidney specific sections to members for comment.

**A Bradley**

#### 3.2.1.1 **Contraindications for use of DCD donor organs**

3.2.1.1.1 In order to provide clear guidance for SNODs, a small working group has been established to agree contra-indications for the use of donor organs. Once developed, these will be circulated to Advisory Groups.

#### 3.2.2 **Non-compliance: CGMG 423/110 Unused kidneys – KAG(11)3**

3.2.2.1 Prof Neuberger highlighted an incidence of non-compliance where three kidneys were not used. The transplant centre involved had planned to transplant four kidneys on the same day. Due to a delay caused by complications with transplanting the first kidney the remaining organs had been overlooked.

It was highlighted that many centres do not have twenty four hour recipient co-ordinator cover, which may have prevented this situation occurring. Members commented that providing this cover by recipient co-ordinators would have a huge impact on resources. In many centres this role is covered by the clinicians on call. Prof Bradley agreed to write to Directors of Transplant Centres asking for reassurance that systems are in place to prevent the acceptance of organs that the centre is subsequently unable to transplant. Ms Marson added that this information would also form part of the CIT project currently being undertaken by Sussie Shrestha, a Clinical Research Fellow at Edinburgh.

**A Bradley**

#### 3.2.3 **CUSUM signals**

3.2.3.1 A number of signals have triggered, of which some were for recipients of kidneys from living donors. In light of this, kidney and pancreas triggers are being monitored to check that the setting is not over-sensitive.

- 3.3 **EU Organ Directive – KAG(11)4a & 4b**
- 3.3.1 The HTA will act as Competent Authority (CA) for the whole of the UK. NHSBT is required to have a procurement licence, whilst every transplant centre is required to have a procurement and transplant licence. The fee for these licences is, as yet, undetermined.
- The Directions are currently being developed, followed by a three-month consultation period on the draft legislation which is due to commence on 1<sup>st</sup> August 2011. In response to a query regarding licenses for retrieving tissue for transplant and for research purposes, Prof Neuberger advised that this is being discussed with the HTA.
- 3.4 **Advisory Group work plan – KAG(11)5**
- 3.4.1 Members received and noted the work plan for KAG. Members were reminded that any other work requested by the Group that requires resource from Statistics and Clinical Audit would need to be slotted into this work plan
- 3.5 **Retrieval and Donated Organs Monitoring Group – KAG(11)6**
- 3.5.1 The terms of reference of a new Group looking at the governance of retrieved organs to ensure they are used appropriately and effectively was received for information. It was noted that the title of this Group had changed following development of the Terms of Reference and it is now known as the Clinical Retrieval Group.
- 3.6 **IT work**
- 3.6.1 **Advisory Group Chairs: IT priority proposals (for info) – KAG(11)7**
- 3.6.1.1 A progress report on the implementation of IT projects by NHSBT was received for information. Prof Neuberger underlined the need for requests for work to be flagged early. These would then be implemented by agreed set dates.
- 3.6.2 **IT implementation of Advisory Group requirements – KAG(11)8**
- 3.6.2.1 A number of important enhancements to IT systems at ODT were implemented on 14<sup>th</sup> April 2011. Included in these were minor changes to the National Kidney Allocation Scheme as well as the addition of new questions to the kidney transplant record form, to identify antibody incompatible transplants, and to the kidney donor form.
- 3.7 **Meeting with patients' groups**
- 3.7.1 Prof Bradley reported on the meeting held in March with representatives of patients' support groups. At that meeting data was presented on kidney transplant activity including living donation and both DCD and DBD donation. Representatives were also informed of the work being undertaken by NHSBT on the selection and allocation policies.
- 3.8 **Data access policy – KAG(11)9**
- 3.8.1 Members received and noted a policy for access to data and information through Statistics & Clinical Audit at NHSBT. This is a formal framework which clarifies how data held by NHSBT can be

accessed and used by:

- individuals or groups within NHSBT
- those with advisory roles to NHSBT
- those within the wider NHS
- those from other organisations with an interest in organ donation and transplantation members of the public.

The policy also defines the process for obtaining guidance when resource is not sufficient to meet demand or requests are not deemed appropriate or when considerable resource is required.

## **4 SCIENTIFIC ADVISOR'S REPORT**

### **4.1 HLA donor discrepancy follow-up: 2010 – KAG(11)10**

4.1.1 Currently, donor HLA type is submitted to the Duty Office on a tissue typing form from a 'tear-off' pad. In most laboratories the HLA type is manually transcribed from the laboratory reporting system onto the ODT form; however in some laboratories the ODT form has been replicated in the local laboratory system and the HLA type automatically downloads into the fields required, thus reducing the risk of transcription errors in donor HLA types. Upon receipt of the type at the Duty Office automated consistency checks take place when the information is entered onto the national database. Any errors detected at this stage are pre-allocation and result in the laboratory being contacted with details of the error message. Errors in the HLA type may also be identified after the organs have been allocated when, for example, another laboratory may detect a discrepancy.

In an attempt to further minimise the risk of incorrect data entry, procedures in the Duty Office have been reviewed and further training provided. The ODT form (TT1) has been produced in electronic format to reduce the possibility of hand written reports being misread. It is, however, not possible to transmit the form electronically to the Duty Office. Members agreed that, in addition, laboratories should be encouraged to make whatever systematic changes are possible in order to reduce this small number of errors.

Dr Fuggle reported on the results of HLA donor discrepancy monitoring for 2010. The level of discrepant donor HLA types reported to ODT and used for allocation purposes is 1.6%.

Members were asked to consider the wording of the Department of Health list of 'Never Events' in relation to the transplantation of ABO or HLA-incompatible organs. Any concerns around registering this type of transplant as a 'Never Event' should be forwarded to the Department of Health. Prof Bradley added that he would be writing to the Department to reinforce his views on this being listed as a 'Never Event'.

**A Bradley**

#### 4.2 **Minimum resolution for reporting donor and recipient HLA types - KAG(11)11**

- 4.2.1 Members noted a paper on compliance with the reporting requirements for HLA types. High levels of compliance are now routinely achieved. Compliance levels in the last six months (October 2010 to March 2011) and the previous six months (April to September 2010) were 99.6% and 100% respectively for deceased donor HLA types; 99% and 95% respectively for recipient HLA types; and 99.8% in both time periods for living donor HLA types.

### 5 **STATISTICS AND CLINICAL AUDIT REPORT**

#### 5.1 **Summary of work – KAG(11)12**

- 5.1.1 Members received a summary of the work of the Statistics & Clinical Audit Directorate in relation to kidney donation and transplantation. In order to improve access to information for transplant professionals, the ODT website is being reviewed and a micro-site is being developed to enable information to be provided in a more logical and easy-to-find structure, with more comprehensive reporting.

Members also noted that various papers relevant to the work of KAG are currently in progress, as well as ongoing kidney and pancreas research proposals using data held on the UK Transplant Registry.

### 6 **REPORT FROM THE DCD KIDNEY ALLOCATION WORKING PARTY HELD ON 1 APRIL 2011 – KAG(11)13**

- 6.1 Dr Raftery summarised the discussion from the DCD KAWP meeting held on 1<sup>st</sup> April 2011:

- HLA typing prior to procurement will be a major issue on the allocation of DCD kidneys and will need to be addressed before progress can be made.
- Kidneys from DCD donors over the age of 60 would be excluded from sharing although it was accepted that some of these kidneys will be shared as they will be retrieved from a centre that does not transplant kidneys from donors over 60.
- In order to inform discussion on recipient pool sizes, views have been requested from Renal Transplant Centre Directors on geographical and local alliances as well as confirmation of local allocation rules.

Following on from discussion on the issue of HLA typing prior to procurement, Prof Bradley agreed to ask Transplant Centre Directors to identify, wherever possible, one or more H & I laboratories within their geographical area that could undertake out-of-hours HLA typing.

**A Bradley**

## **7 REPORT FROM THE HLA MEETING ON 20 APRIL 2011 – KAG(11)14**

- 7.1 On 20<sup>th</sup> April 2011 Prof Neuberger chaired a meeting, on behalf of NHSBT, to bring together all interested parties to identify solutions to delays in obtaining donor HLA types; and to develop a national specification for efficient HLA typing, to be supported by professionals primarily through the BTS and BSHI. A draft specification for the provision of deceased donor HLA offer typing was discussed at the meeting and revisions were recommended. A proposed pathway, incorporating this specification, will be developed and, in the meantime, Prof Neuberger reported that he had met with NSCT to try to identify where the funding for HLA typing currently sits so that it can be incorporated into the retrieval costs in order to ensure transparency in charging, including tissue typing for non-proceeding donors. It was acknowledged that the funding could take some time to unravel.

## **8 PATIENT SURVIVAL FROM LISTING – KAG(11)15**

- 8.1 Members received an initial analysis examining long-term patient survival from transplant listing and whether there is any variation across transplant centres. Ten-year patient survival from the point of listing on to the adult kidney-only transplant list is 72%; however there is significant variation across centres. It was noted that many important factors likely to explain much of the variation across centres, which may not be directly linked with the transplant centres, have not been accounted for in this analysis. Members commented that the proportion of dialysis patients either on the transplant list or transplanted should be added to the analysis including data on survival after transplantation. Another change requested was to de-anonymise centres on the report. An updated report will be submitted to the next KAG meeting.

**A Hudson**

## **9 DUAL KIDNEY TRANSPLANTATION**

### **9.1 Setting the scene – KAG(11)16**

- 9.1 A paper was received aimed at determining if there is any potential for more dual kidney transplants (DKTs) in the UK and to identify the types of donors whose kidneys are used in DKTs compared with single kidney transplants (SKTs). This paper was produced to provide preliminary information for further discussion in relation to the proposal at 9.2 below.

From January 2001 to April 2011 there were 94 DKTs, the vast majority being from DCD donors. Preliminary results for donors meeting the proposed dual criteria indicate there is no difference in graft and patient outcome for dual and single kidney transplants, although superior graft function in terms of eGFR is observed for such recipients of DKT when compared with SKT at three months post transplant. The analysis seems to support current practice with regard to use of such donors for single kidney transplantation. However, preliminary results suggest that there may be potential to

increase the number of dual kidney transplants without affecting the pool of kidneys used for single kidney transplantation, ie currently unused DCD donor kidneys.

## 9.2 **Proposal for dual kidney allocation and a prospective study of the outcome of such allocation – KAG(11)17**

9.2.1 Following on from discussion at 9.1 above, Mr Ahmad submitted a proposal for the utilisation of kidneys from extended criteria donors (including DCD donors). Members were supportive of a sharing scheme but there were concerns that the transplant community would not agree to the proposed criteria. KAG agreed that further analysis of UK data should be undertaken, although in what format was unclear as data on GFR is not currently collected. Mr Ahmad would liaise with the Statistics & Clinical Audit representatives to decide on the best course of action. The proposal for a study of prospective allocation of dual grafts was not supported.

**N Ahmad**

## 9.3 **Proposal to set up a UK registry for dual kidney transplants – KAG(11)18**

9.3.1 Further to discussion at 9.2 above, it was agreed that it was not appropriate at this time to proceed with the establishment of a UK registry for dual kidney transplants until further work detailed in 9.2 above has been investigated.

## 10 **LIVING DONATION UPDATE – KAG(11)19**

Ms Burnapp summarised a review of the National Living Donor Kidney Transplant Programmes. The findings of the review were presented to the Senior Management Team at ODT and approved in principle. KAG members approved the following recommendations:

- An event involving key stakeholders within the wider transplant community should be held to launch the Living Donation Strategy.

It was felt that this could be incorporated into the Renal Transplant Services Meeting in January 2012.

- A project group with representation from key stakeholders across the transplant community should be appointed to develop an implementation plan for the Living Donation Strategy. Clinical representation will be recommended through the appropriate NHSBT Advisory Groups (KAG and LAG).

KAG members supported the development of a strategy along the themes outlined. The strategy will be presented to the NHSBT Board in July. Members were of the opinion that NHSBT should provide an overarching educational support role through Ms Burnapp. It was also felt that when developing the infrastructure to support pre-emptive live donation this should also be looked at in the context of deceased donation. The thresholds would not need to be the same nor would they have to be implemented at the same time.

Members were advised to contact Ms Burnapp if they would like to be involved in taking this forward. Ms Burnapp agreed to liaise with Dr Tizard re paediatric input.

**L Burnapp**

10.1 **Domino kidney donation – KAG(11)20**

10.1.1 Ms Burnapp put forward a proposal for a change in the allocation system relating to domino kidney donation. This would involve the adoption of local allocation for kidneys donated as a result of a domino procedure rather than according to national allocation criteria. The kidney would be allocated in advance to a local recipient through the ODT Duty Office. It is unlikely that there would be a major impact on the allocation system due to the small number of cases of domino kidney donation. KAG members approved the change and Ms Burnapp agreed to forward details of the change to the allocation policy to Kate Avery at Synergy to be incorporated into the kidney allocation policy currently being finalised.

**L Burnapp**

10.2 **Altruistic and paired donation update – KAG(11)21**

10.2.1 Members received and noted a report giving an update on progress with the altruistic and paired living donor kidney transplant programmes. One term has now been agreed to encompass both schemes and this is the National Living Donor Kidney Sharing Scheme. This will incorporate:

- Non-directed altruistic donation (NDAD) (direct to deceased donor transplant list)
- Paired/Pooled donation
- Altruistic donor chains (where NDAD donate to the paired/pooled scheme)

Details on altruistic donor chains will be available for transplant centre staff and for potential donors and recipients in July with the expected first run of the new scheme in October 2011.

Prof Bradley reminded members that donors now need to be consented for what should happen if a living donor kidney cannot be transplanted in the intended recipient. This consent process will need to take place prior to the independent assessment of the donor.

In response to ongoing concerns about the cost of altruistic donor work-up Ms Burnapp is incorporating into the guidelines an algorithm which suggests a model pathway, developed with the assistance of colleagues from those centres involved with the majority of altruistic donors.

**11 BIOPSY OF DONOR KIDNEYS**

11.1 This item was carried forward for discussion at a future meeting.

**A Bradley**

**12 KAG PAEDIATRIC SUB-GROUP: REPORT FROM THE MEETING ON 27 APRIL 2011**

12.1 Dr Tizard reported on the key points from the meeting:

- Changes to the 2006 National Kidney Allocation Scheme resulting in paediatric patients appearing in Tier D of future matching runs having enhanced HLA match/age points.
- A study on the reasons for decline of kidney offers for paediatric patients is progressing.

- A review of the last 20 years of paediatric kidney transplantation in the UK is being written with a view to submission of an extract to an appropriate external meeting.

Expressions of interest for the Chair of KAGPSG have been invited from members of the sub-group. As the current Chair of the Paediatric Sub-Group is also the BAPN representative on KAG, members were asked to approve an additional representative on the membership of KAG so that both BAPN and the Paediatric Sub-Group are represented on KAG. Members agreed to an increase in the membership for this purpose.

### **13 REPORT FROM PANCREAS ADVISORY GROUP**

13.1 Prof Friend reported on the key points from the most recent Pancreas Advisory Group meeting:

- The Pancreas Allocation Scheme has been introduced and is working extremely well.
- The number of long waiters has decreased.
- The number of transplants has decreased.
- There were concerns about delays in obtaining HLA types.
- Delays in the offering of pancreases to islet isolation labs are causing problems.

### **14 FOR INFORMATION ONLY**

14.1 **Update on renal patient consent scheme & living patient consent scheme - KAG(11)23a & 23b**

14.1.1 An update on both the renal patient consent scheme and the living patient consent scheme were received and noted.

- Of the 10,584 patients who were registered on the national list for a renal transplant, 95% have given consent for the use of their personal data.
- Of the 2,095 patients who were registered on the national list for a living kidney donor transplant, 99% have given consent for the use of their personal data.

14.2 **Transplant activity report: April 2011 – KAG(11)24**

14.2.1 The transplant activity report for April 2011 was noted for information.

14.3 **Non-retrieval and non-use of organs - KAG(11)25**

14.3.1 Members received and noted a paper detailing rates and reasons for the non-retrieval and non-use of kidneys.

14.4 **Protocol for clinically urgent scheme for paediatric patients awaiting renal transplantation – KAG(11)26**

14.4.1 Members noted for information the above protocol.

14.5 **Updated Kidney Allocation Scheme protocol – KAG(11)27**

14.5.1 An updated version of the 2006 Kidney Allocation Scheme as at April 2011 was received for information.

**15 ANY OTHER BUSINESS**

15.1 There were no other items of business.

**16 Date of next meeting**

16.1 The next KAG meeting is scheduled for Wednesday 7<sup>th</sup> December 2011 at ODT, Bristol

**Organ Donation & Transplantation Directorate**

**September 2011**