



The new professional development programme is planned out in great detail

promote local initiatives is another component of the course.

**Map of Medicine**

Another strand to the programme will be to develop care pathways of best practice in donation. This work will be undertaken by Subject Matter Experts in conjunction with Map of Medicine a web based application designed to define standards of best practice along a clinical pathway.

Versions of these pathways will be freely available on the web for anyone to see in England and Wales and a solution is being sought for Scotland and Northern Ireland.

Regions will have localised versions and be able to personalise content.

Paul Murphy, National Clinical Lead, who is overseeing the project said "For people working in this field, this programme offers a great introduction into the many different skills required and will give them a real understanding of how organ donation can be improved. We are delighted to be working with Deloitte on this project and anticipate it being a very lively and popular course."

Lesley Logan, Business Lead for the project said: "Organ donation doesn't happen by accident, even

the most naturally talented people need proper, high quality training in order for them to realise their full potential. NHSBT places a high priority on training and we're delighted to be involved in this joint venture with Deloitte. We hope that this programme will pave the way for other training and educational partnerships."

Sir Bruce Keogh, NHS Medical Director says "This exciting, innovative programme will not only give you skills to increase organ donation in your hospital but will support leadership to the benefit of the whole NHS'.

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**Ocular Tissue Advisory Group**

OTAG met on 1 July 2009

■ The bone and tissue sub-group of SaBTO have reviewed the issue of potential donors with a history of blood transfusion and accepted that eye donors with a history of blood transfusion should continue to not be excluded from eye donation. This matter will be kept under review.

■ Work is ongoing around financial disincentives to trusts in relation to eye donation and retrieval. If co-ordinators wish to be trained in eye retrieval then NHSBT will support this request but there is no absolute requirement for them to do so as part of their role.

■ Work is still ongoing into working out the best method of capturing information on what techniques surgeons are using to insert the graft for endothelial keratoplasty.

■ Work is ongoing to put in place a mechanism for central serology testing. Provision of funding has been agreed with NHSBT. Christmas transport issues have been resolved by local storage of blood until transport is available.

■ A workshop has been held looking at different models for setting the new HTA licence fees. A consultation paper will be produced with a different model for fixing fees.

■ Amendments have been proposed to the transplant record and follow-up forms and these changes will be progressed. Ten-year follow up forms have been piloted in certain centres and will be sent out on a monthly basis to collect ten-year data. If the data is available a long term project will be defined.

■ A protocol is to be drafted for a review of outcomes of transplants for patients who have undergone both a corneal and a solid organ transplant. Interested parties in other countries are to be contacted to ask if they would like to participate in this project.

■ The outcome of paediatric corneal transplants is also being audited.

■ Centre specific reports are to be produced to bring OTAG in line with the solid organ advisory groups. These would be in the form of funnel plots on corneal transplant outcomes for centres. The outcomes would be for first transplant for keratoconus with variables for penetrating keratoplasty and deep anterior lamellar keratoplasty and outcomes for Fuchs Dystrophy with variables of penetrating keratoplasty and endothelial keratoplasty.

■ The number of corneas issued and not used is not reducing and it was suggested that these should be offered to those surgeons who are struggling to obtain corneas via the fax system.

■ Compared with the previous financial year, there was an increase in the number

of eye donors from solid organ donors from 200 to 249. There has also been an increase from 24 to 60 in the number of eye donors from heartbeating and non-heartbeating donors where solid organs were not donated.

- 88% of corneas retrieved by Moorfields and 63% of corneas retrieved by East Grinstead are kept locally and not sent to a CTS eye bank for national allocation. It was, however, acknowledged that the waiting time for patients at Moorfields, along with allocation policies were similar to that of other major centres. The allocation policy for solid organ donation involves HLA matching so those patients who require HLA matching are significantly disadvantaged as they don't have access to the full donor pool of eyes. It was felt to be inappropriate for a patient to have increased access to a corneal transplant from locally retrieved tissue. It was suggested that eyes from solid organ donors, and which are therefore HLA matched, be exchanged with the CTS eye banks to ensure that all patients have access to eyes from HLA matched donors. There were concerns that these centres would then incur a financial disadvantage from this arrangement. Before a decision is made, further information is needed on corneas required and issued, and allocation policies from non-CTS eye banks.

- A proposal was endorsed for the prioritisation of eye retrieval as soon as possible after post-mortem in order to maintain the quality and safety of ocular tissue for transplantation. Unnecessary delays in retrieval should be avoided and, in particular, eyes from solid organ donors should be removed in theatre, either before, during or following solid organ retrieval.

- Following investigation into the requirements of the EU Directive on Tissue Donation and enquires with the Human Tissue Authority for their view it was confirmed that NHSBT will not be exempt from implementing consent arrangements in ocular transplant centres. There is an expectation, therefore, that NHSBT will continue to make progress in the area of consent with all centres during the next year. Members repeated their concerns that the requirement to obtain patients consent for use of their information would affect the legal requirement on centres to capture serious adverse event reporting. However, a pilot study will be established to take this forward. If appropriate, evidence from the pilot will be presented to the National Information Governance Board to support members' concerns.

- From mid-January to the end of April the demand for corneas averaged 200 requests per calendar month which were successful and around 35 – 40 that were unsuccessful (although some of these may have gone on to have a graft

in the following week or weeks). Work is underway to access details on the number of patients waiting for a corneal transplant (to include scleral graft or corneas for glaucoma procedures) in order to estimate the demand for corneas for NHS entitled patients.

- Some surgeons have reported difficulties with the fax ordering procedure for corneas via the ODT Duty Office and of increases in the waiting time for surgery. The Duty Office is to investigate ways of monitoring the allocation of corneas by surgeon, centre and region.

- A proposal to widen the remit of OTAG to include two further ophthalmic products, amnion and autologous serum eye drops (ASE) was put forward. This would present a cohesive service to the users of NHSBT's ophthalmic tissue grafts, products and service. However, queries were raised around the process for monitoring outcomes of users of these products and the follow-up arrangements, which are currently not tracked. This may have significant impact on IT resourcing if required. The proposal was agreed in principle but further detail is required on the implications of such a proposal and the numbers involved. The question of the inclusion of plasminogen eye drops for ligeneous conjunctivitis was also raised.

- One of the remits of OTAG is to maintain the standards of eye donation and transplantation which includes donor selection policies. It was agreed to support formalisation of the process of eye donor selection criteria via the Standing Advisory Committees (SAC), such as that for Tissues (SAC-T) to the Joint UK Blood Transfusion Services and National Institute for Biological Standards and Control Professional Advisory Committee (JPAC) with additional expert advice on eye conditions to OTAG from the Ocular Tissue Transplant Standards Group of the Royal College of Ophthalmologists (OTTSG) and other groups. Issues regarding selection criteria would be taken via OTAG to the SAC and JPAC.

- The standard operating procedure for reporting of serious adverse events was established. The outcome of serious adverse events reporting (SAER) from Moorfields will be provided to the OTAG audit group monitoring SAER.

- A draft protocol categorising adverse events & reactions from donation to transplantation was supported and commended. This would be subject to further review and then re-circulated.

- Advice and procedures for dealing with issues of retrieval involving junior doctors will be sought from OTTSG and the Professionals Standards group as necessary.

- Eye retrieval boxes should contain verification of document version and expiry date. This will be followed up with the company supplying the boxes

and the respective hospitals. Centres carrying out eye retrieval should check the boxes for expiry dates and report any issue relating to this.

- The following items were those raised at OTTSG:

- An update was given on the preparation of dissected ocular tissue by the eye banks. Two automated keratomes will be evaluated at the next eye bank meeting.

- There is currently no known method of identifying eyes that have undergone laser refractive surgery. As the numbers are thought to be low it was decided to postpone this discussion. In the meantime, donors with a history of laser surgery will still be excluded. Eyes from these donors may be able to be used for DSEK but no final decision has yet been reached on this proposal. This will be discussed at the next meeting of OTAG.
- On behalf of OTTSG and OTAG the College newsletter included a reminder highlighting the need to return forms to ODT.

- A Group 2 paediatric patient visiting the UK for a medical assessment suffered a spontaneous rupture of the cornea. The Eye Bank was unable to supply any material for this case as Department of Health regulations state that if patients come to the UK for the purpose of obtaining health treatment they must be prioritised below Group 1 patients. In this case tissue was obtained from the EU for the patient but the question was raised as to whether other options would have been available. A clear clinical need was recognised and clarification will be sought on whether corneas are classed as tissues and are therefore not subject to Group 1/2 definition.

## Cardiothoracic Advisory Group

CTAG met on 23 September 2009

- The 18-month fellowship in cardiothoracic transplantation at Papworth Hospital has now been filled and the second round of appointments is ongoing for the second fellowship to be based at The Freeman Hospital, Newcastle. Additionally, bids have been submitted to NCG and DH for funding to continue with the programme. Once information on 2011 funding is available then the process to accredit a training programme with the SAC can be progressed.

- The first issue of the hospital trust reports from the potential donor audit were distributed to centres in August to benchmark this against national data. The revised Potential Donor Audit (PDA) is expected to go live after testing on 1 October 2009, which will ensure the provision of timely data to centres. CTAG members requested to be able to see data on individual hospitals.

- The current offering principles for lungs are currently under review.

- Following the independent report on the allocation of organs to non-UK EU residents the DH implementation group has met and will be submitting recommendations to Ministers. At the present time the status quo remains, with no change to the current practice with regard to EU or Group 2 patients.

- As part of the changes to Advisory Group arrangements, instead of having patient representation on the membership of each advisory group an annual meeting will be held with a selection of representatives from patient support groups for each organ. It is hoped to arrange a meeting with the cardiothoracic patient support groups in January 2010.

- To provide for consistency of terminology the databases currently hosted by NHSBT are now referred to as the UK Transplant Registry rather than the National Transplant Database. This will not affect the way in which the data is collected.

- Mrs Rachel Johnson has been appointed to the new post of Head of Organ Donation and Transplantation Studies, with responsibility for the co-ordination of the work allied to the ODT Directorate of NHSBT.

- A new forms development IT infrastructure is being developed as a joint project between NHSBT and consultancy firm Sapient. Four cardiothoracic registration forms are being developed using this new infrastructure.

- In relation to the national heart sharing scheme for sensitised patients, concern was expressed regarding the variation in practice between laboratories. A BSHI ABO special interest group will be meeting shortly focusing on antibody definition of matchability. CTAG concerns will be fed back to BSHI with a request for harmonisation in the reporting for cardiothoracic allografts.

- NHSBT have agreed to support a working group between NHSBT and the British Society for Heart Failure to work on developing referral, selection and allocation criteria for heart transplantation. It is intended that these will eventually be incorporated into PCT and national guidelines. Liaison is also taking place with cardiology groups to incorporate these into the cardiology curriculum.

- Clear guidelines will be developed following a review of internal centre allocation criteria for heart and lung transplantation.

- The audit fields for all potential transplant referrals will be developed by the UKCTA-NHSBT project group and incorporated into the NHSBT datasets. CTAG will consider where this sits in the IT priorities of NHSBT. In terms of IT priorities this piece of work was

prioritised behind the transplant record form and follow-up forms.

■ A small working group will be convened to review the International Society for Heart and Lung Transplantation (ISHLT) guidelines for referral for lung transplantation and produce a strategy for their wider dissemination within the UK. This working group will also review listing criteria and referral criteria for lung transplantation.

■ At present any reviewed allocation system will retain zonal primacy for non-urgent allocation until more information is available. The principle of regional zones will be based on geographical proximity therefore the existing primacy zones should not change ie 1st option – local centre; 2nd option – accepting centre (if able to retrieve in time); 3rd option – next closest local centre. A further review, once robust data is available on selection criteria and referral patterns will be considered once data is available in two years. The issue of time allocation for donor management and the need to make provision for how this care is provided is being considered by NHSBT at the present time. Until a decision is made on which option to take forward it is unlikely that any training in donor management will happen until 2010/11. Members expressed concern at these delays and suggested that NHSBT should consider ways of supporting centres in funding local solutions in the interim.

■ CTAG endorsed a recommendation that the differential organ donation rates, centre attendance and organ yield by retrieval zone should be further explored by a UKCTA-NHSBT project group. Reasons for low donation, attendance and retrieval rates should be defined if possible to allow corrective action to be taken.

■ CTAG endorsed a proposal to move towards more comprehensive donor assessment systems. The UKCTA-NHSBT project group and the two working groups for heart and lung allocation will be asked to consider how to incentivise and reward good retrieval practise and high yields.

■ CTAG endorsed a strategy that enables greater donor assessment towards heart and lung donation and a system that re-offers once assessment (but not management) is complete.

■ The payback scheme under its current

rules will be continued subject to better information on referral, selection and retrieval.

■ A short term working group will be established to review options for organ allocation, including the current system, systems used elsewhere internationally, and systems used for other solid organs.

■ Arising from concerns raised previously regarding hearts from 'large' adult donors being transplanted into paediatric patients, some proposed rules regarding size matching for non-urgent paediatric patients were submitted for consideration. Following simulation the scheme proposed would affect 9% of all paediatric heart transplants over a recent three year period and would protect eight large adult donor hearts from being used in much smaller paediatric patients. Further work on this proposal is required to fine-tune the detail and a revised proposal will be produced.

■ With regard to the issue of equity of access between the two paediatric centres, Newcastle will retain its access to zonal donors for paediatric patients rather than moving to a preferential offering system on a rotational basis with Great Ormond Street.

■ In July NHSBT received notification from Swisstransplant about the introduction of a new European Children's Heart List (ECHL) for all patients up to 12 years of age awaiting heart transplant. Details of the list were sent to Great Ormond Street Hospital and The Freeman Hospital, Newcastle, following which both centres have expressed an interest in registering their patients on the list. Only national organ allocation organisations will have access to the list meaning that NHSBT would be responsible for registering patients in the UK. Work is ongoing to resolve data security concerns in terms of UK requirements.

■ An extension to the payback scheme was implemented on 16 January 2009, such that those centres which export a heart for use in an urgent patient are promoted to the top of the out-of-zone offering sequence and remain there until they have received a heart for a non-urgent patient from outside their zone, when they are then demoted. This extension to the scheme is subject to specific promotion and demotion criteria. The extended scheme will

continue to operate for a further six months and will be reviewed at the next CTAG meeting.

■ Proposed inclusion/exclusion criteria for listing paediatric patients on the urgent heart scheme were agreed at the March 2009 CTAG meeting. The inclusion criteria, incorporating changes agreed by the two paediatric centres, were split into categories that broadly mirror those used for adult urgent patients. The new codes will be circulated to the paediatric centres for use from 1 October 2009.

■ The views of CTAG were sought by the Health Commission for Wales on the principle of undertaking desensitisation before cardiac transplantation for highly sensitised heart patients and on the ethical issues of the duration of desensitisation. Below is a summary of CTAG's response:

- CTAG is not the responsible body for determining the appropriateness of individual patient therapies, nor does it have commissioning within its terms of reference; the infrastructure to support detailed literature reviews or the skills to assess cost effectiveness.
- The decision to use a desensitisation procedure rests with the individual centre and is subject to its own clinical governance procedures.

■ In view of the uncertainty about the clinical outcome that can be achieved, the centre should seek a suitable donor from its own zone or through the standard non-urgent national offering sequence. The question of whether desensitised patients should be admitted onto the yet to be implemented sensitised patient scheme will need further debate at CTAG and expert guidance.

■ In the absence of a funded national study, the responsibility for funding the procedure lies primarily with the individual centre and its commissioners.

■ While a centre may request additional funding for such a procedure, the limited evidence on clinical effectiveness and lack of evidence of cost effectiveness would mean that such a request would be on a 'compassionate use' basis. A situation in which funding were diverted in a way that would disenfranchise patients otherwise suitable for transplantation could not be supported.

■ It is desirable that commissioners should either develop a pilot study

of desensitisation or obtain a formal review of the current evidence at the earliest practicable opportunity.

■ Currently there is no national sharing scheme for lungs and there appears to be no universal approach to desensitisation. There is a need to review policy within different centres and to produce allocation guidance on sensitised patients listed for lung transplantation. This work will be incorporated within the remit of the working group reviewing listing criteria and referral criteria for lung transplantation.

■ The policy on when a paediatric donor should be attended by either an adult cardiothoracic retrieval team or a specific paediatric team was submitted to CTAG for clarification. Newcastle is currently the only centre providing a service for both adult and paediatric donors; whilst Papworth, Harefield, Birmingham, Glasgow and Manchester each provide teams based upon adult heart and lung transplant programmes; and Great Ormond Street field a 'small paediatric' team on an ad-hoc basis when necessary. In view of the new retrieval arrangements a cut-off point of 11 years or 30kg in terms of donor size was agreed above which the adult team can provide a competent service.

■ No revisions were proposed to the National Standards on Documentation for Cardiothoracic Transplant Patients. This document will next be reviewed in September 2011.

■ The review of the National Protocol for Assessment of Cardiothoracic Transplant Patients is to be postponed as this will fall within the remit of the working group on referral and listing for heart transplantation. In addition a review and debate on national selection criteria will need to be carried out once 1 year's data has accrued from the new registration forms to be introduced shortly.

■ Proposed revisions to the Donor Retrieval Process for Heart and Lungs were requested. At some time in the future this document may need to be incorporated into a national donor management and retrieval document.

■ CTAG supported a proposal from Papworth for a combined lung/liver transplant programme between Papworth and Addenbrooke's. Several centres are currently considering this type of combined programme.

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