

**UK TRANSPLANT
SPECIAL HEALTH AUTHORITY**

**MINUTES OF THE THIRTIETH MEETING
OF THE SPECIAL HEALTH AUTHORITY
HELD AT 12:00 NOON ON MONDAY, 1 MARCH 2004
IN CONFERENCE SUITE 2, UKT, BRISTOL**

PRESENT:	Gwynneth Flower	- Chairman
	Margaret Branthwaite	- Non-Executive Director
	Dave Collett	- Director of Statistics and Audit
	Martin Davis	- Director of Finance
	Sue Falvey	- Director of Donor Care & Co-ordination
	Neil Goodwin	- Non-Executive Director
	Penny Hallett	- Director of Communication & PR
	George Jenkins	- Non-Executive Director
	Judith Mackay	- Non-Executive Director
	Alistair McGilchrist	- Non-Executive Director
	Chris Rudge	- Medical Director
	David Shute	- Director of IT and Support Services
	Sue Sutherland	- Chief Executive
IN ATTENDANCE:	Kathy Cardwell	- Secretary
	John Forsythe	- KPAG Chairman (presentation only)
	Jane Griffiths	- Observer

The Chairman welcomed and introduced Mr John Forsythe, kidney transplant surgeon at the Royal Infirmary of Edinburgh and Chairman of the Kidney and Pancreas Advisory Group. Mr Forsythe gave an interesting presentation covering kidney transplantation and the work of the Kidney and Pancreas Advisory Group.

APOLOGIES

Apologies were received from Gilbert Park and Gurch Randhawa.

1 DECLARATIONS OF INTEREST IN RELATION TO THE AGENDA

1.1 No Member present declared a conflict of interest in relation to the agenda.

2 REPORT BACK FROM AUDIT COMMITTEE MEETING HELD EARLIER

2.1 George Jenkins reported to the Board on the Audit Committee meeting and specifically on concerns surrounding the audit fee. It was noted that the Authority had no choice but to accept the auditor appointed and therefore their fee. However, further evidence had been requested to justify this figure.

3 MINUTES OF THE AUDIT COMMITTEE MEETING HELD ON 25 NOVEMBER 2003 – UKTAUDIT(M)(03)3

The Minutes of the meeting were accepted.

4 MINUTES OF THE 29TH MEETING OF THE SHA HELD ON 22 JANUARY 2004 - UKT(M)(04)1

4.1 The Minutes of the meeting were agreed and signed as a true and correct record.

4.2 Action Points – UKT(AP)(04)2

- 1 Screening for pregnancy of female potential donors: The Medical Director reported that he would be speaking to a representative from the Royal College of Obstetrics and Gynaecology for advice. This would then be discussed at the Advisory Groups in due course.
- 2 Review of allocation rules re legally incompetent adults: This issue would be discussed at Advisory Groups during 2004 and outcome reported back to the Board at the end of the year.
- 3 Extension of data collection contract: The Director of IT & SS confirmed that that paper had been submitted to the Audit Committee and approved.
- 4 Patient consent scheme: The Director of IT & SS confirmed that contact had been made with the National Joint Registry and some useful approaches will be adopted for the patient consent pilot scheme.

4.3 Matters arising, not previously identified

Item 5.2: Margaret Branthwaite questioned the liability of the Health Authority in relation to advice given by its expert advisory groups such as the management of potential organ/tissue donors with positive virology results. The Chief Executive confirmed that the authority is liable for its actions and therefore needs to consider carefully the implications of implementing advisory group advice that may attract significant liability.

5 FINANCE AND BUSINESS PLANNING

5.1 Financial Report to 31 January 2004 – UKT(04)13

5.1.1 Members noted the report on the financial position as at the end of January and that £750,000 had been brokered over the year-end. There is an underspend of £179,000 as at 31 January and, after taking into account brokerage, the Authority is on course for a break-even position at year-end

5.2 Activity Report – January 2004 – UKT(04)14

5.2.1 The Chief Executive outlined a summary of the performance on transplantation to the end of January 2004. Members noted the decrease in heartbeating donors and increase in both non-heartbeating donors and living donors compared to last year. The high relative refusal rate is known to have been a significant factor in the decrease in heartbeating donors. It is still unlikely that the annual target for kidney or liver transplants will be achieved, although a busy February to date may impact on year-end outcomes for kidney transplants. Numbers of people registered for heart/lung transplants continue to decrease significantly whilst those registered for a lung transplant continue to increase.

6 PAPERS FOR APPROVAL

6.1 **Business Plan 2004/05 – UKT(04)15**

6.1.1 The Chief Executive had amended the draft Business Plan following its submission to the Board in November and discussions with the Health Departments in England, Wales and Scotland. The financial framework contained in the plan is still in draft form, and year-end performance cannot be finalised until the end of March. However, after confirmation of a few minor points, Members approved the plan.

6.2 **Organ donor line and fulfilment of organ donation promotional materials contract – UKT(04)16**

6.2.1 The Director of Communications/PR presented a background paper on the recent tendering exercise for the Organ Donor Line and fulfilment of organ donation promotional materials contract. With the expiry of the current contracts at the end of March 2004 it was decided to streamline the management of these services and issue one contract on a three-year basis with annual reviews. Following an extensive assessment process, the UK Transplant panel were recommending the contract be awarded to MM Group. Members approved the awarding of this contract to the lowest tenderer, MM Group, with effect from 1 April 2004.

7 PAPERS FOR INFORMATION

7.1 **Overview of black and South Asian organ donation campaigns 2003/04 – UKT(04)17**

7.1.1 The Director of Communications and PR reported on the dedicated promotional campaigns for black and South Asian groups. Members reviewed the work completed to date on these campaigns and the effectiveness of these within the relevant ethnic groups. Discussion took place on the data showing the proportions by ethnic group on the register in comparison to proportions in the national population. An overview of future campaign strategies includes the Communications team taking a more integrated approach to both campaigns in 2004/05 with external support on a project-by-project basis, thus utilising the campaigns budget more effectively.

7.2 **Further results from the potential donor audit – UKT(04)18**

7.2.1 Following preliminary analyses of data from the Potential Donor Audit (PDA) in November 2003, the Director of Statistics and Audit outlined the results of data for a further three-month period. The overall relative refusal rate for the six-month period April to September 2003 was 43%, although Members noted that this result should be regarded with caution as this was based on relatively small numbers of individuals, plus completed PDA forms for the period are still being received. Further analysis indicates that the relative refusal rate is dependent upon both age group and ethnic group. There is no evidence of significant variation in relative refusal rates between individual hospitals, nor between groups of hospitals. A further report on the data for the nine-month period from April to December 2003 is expected to be issued in May.

8 EXECUTIVE DIRECTORS' REPORTS

8.1 Director of Communication & PR's Report – UKT(04)19

8.1.1 The Director of Communications/PR updated Members on the DVLA “Leave more than memories” campaign. Over 3 million leaflets were distributed during January/February although it is too early to give an indication of the costs/response rate. Further mail-outs are planned for March and April. Together with heavy media and public relations support this campaign has had a sustained impact on calls and registrations. Visits to the UKT website have also increased by 75% over the campaign period.

Members noted new arrangements for Welsh residents to register onto the NHS Organ Donor Register. From 1 April 2004 these calls will transfer from being handled by Lifeline Wales to UKT's Organ Donor Line. Additional funding has also been agreed for UKT to manage the printing of the Welsh bilingual organ donor registration form.

Members were advised that the Council of Ethnic Minority Voluntary Organisations has agreed to run a joint campaign with UKT to increase the number of black and ethnic minority organ donors.

8.2 Director of Statistics & Audit's report – UKT(04)20

8.2.1 The Director of Statistics and Audit reported that the Directorate had submitted 14 extracts for inclusion in the programme of the Conference of the British Transplantation Society to be held in April, all of which were accepted. Details of the abstracts were noted.

8.3 Medical Director's Report – UKT(04)21

8.3.1 A summary of the principal items discussed at the OTAG meeting was given by the Medical Director. The principal item of interest was the report from the Corneal Services Project Group. The Group had undertaken a review of the Corneal Retrieval Service and proposed options for clinical and funding models which would enable corneal retrieval services to be funded in up to eight trusts and would ensure sufficient numbers of corneas for transplantation. It is hoped that the first four units may be established by October 2004.

8.3.2 The Medical Director informed Members that the Scottish Liver Transplant Unit based in Edinburgh is producing a preliminary proposal to the National Services Division for consideration of a living donor liver transplant programme. This follows extensive multi-disciplinary discussions within the Edinburgh unit, as well as efforts to assess public opinion on this subject through press and other media.

8.3.3 At a recent meeting between representatives of Diabetes UK and UK Transplant broad agreement was reached on the necessary process required to establish a database for patient registration, allocation of islets and patient follow-up in relation to pancreatic islet transplantation. This method of treatment for patients with insulin dependent diabetes is currently under development in the UK as a clinical research project, funded by Diabetes UK

8.4 Chief Executive's Report – UKT(04)12

8.4.1 Members noted an update on the progress of the Human Tissue Bill from the Chief Executive. An amendment has been proposed to include a clause transferring the ‘wishes’ of those currently on the register and/or carrying cards to ‘appropriate consent’ on the day the legislation becomes effective. The solicitors acting on behalf of the Authority will continue to monitor proceedings and

provide advice.

- 8.4.2 The Chairman and Chief Executive discussed the future strategic direction for UK Transplant with members of the Arms Length Bodies review team. UK Transplant's relationship with the National Blood Services was discussed and, as a consequence, a copy of the jointly commissioned report with the National Blood Service was submitted.
- 8.4.3 Members noted for information that the Data Services Strategy Board had achieved or was in the process of completing all but one of its recommendations. This Board had therefore now been disbanded. The remaining recommendation relating to the capture of 90% of patient data electronically will be considered as part of the implementation of the national IT programme with the NHS Information Authority.
- 8.4.4 The Chief Executive reported that the Health Minister had met with the Association of British Pharmaceutical Industry to encourage their involvement in work to support the National Service Framework for renal disease. As a consequence of this meeting the Chief Executive met with Department of Health officials and pharmaceutical company representatives to consider opportunities for joint working with the four companies involved.

9 ANY OTHER BUSINESS

- 9.1 The Chairman reported on the recent visit of Aiden Halligan, Deputy Chief Medical Officer, to UK Transplant. The visit was very successful and Directors were asked to pass on the Board's thanks to everyone involved. Professor Halligan had commented on the importance of the work of UK Transplant.
- 9.2 Margaret Branthwaite queried the correct method of disposal of Board papers when Members had finished with them. It was agreed that the Director of IT & SS would produce draft guidance on this matter for consideration at the next meeting.

10 DATE OF NEXT MEETING

- 10.1 The next meeting of the SHA will be on Friday 23 April 2004 at UKT, Bristol.