

New UK Transplant - New Authority - New Board - New Chief Executive

UKTSSA formally became UK Transplant on 12 July. Along with the Authority's new name and new remit the opportunity has been taken to adopt the new corporate NHS style.



This Bulletin mixes the old with the new. The Special Health Authority Board's report to Ministers recording the last year's work of UKTSSA is summarised on page 2. That report describes a busy year with particular attention paid to considering donation and procurement issues and to capitalising on the investment in the National Transplant Database.

At the end of the financial year we lost the valuable contributions of three Non-Executive Members of the Board: Tim Locke and Peng Lee Yap's terms of office came to an end and Brian Fidler, too, stood down. All three provided valuable support to the Authority and we are most grateful to them. We wish them well for the future.

I am pleased to say that Ministers have now appointed three new Non-Executive Directors to see UK Transplant into its first year. We are joined by Dr Chitra Bharucha, formerly Deputy Medical Director of the National Blood Service in Northern Ireland, Neil Goodwin who is Chief Executive of Manchester Health Authority and Judith Mackay from Aston University Media Studies Department.

I am also delighted to announce the appointment of Sue Sutherland as Chief Executive for the new UK

Transplant. Sue's background and experience fit her well for the new challenges facing us. Sue qualified as a registered nurse at University College Hospital, London and as a registered midwife in Chester: after a number of clinical posts primarily in Accident and Emergency Departments in various parts of England she returned to UCH as a Nursing Officer. Sue completed post graduate studies in personnel management and held a number of personnel management posts in the Health Service and for Marie Curie Cancer Care. Sue moved to Devon in 1989 and has held Executive Director posts in Personnel, Nursing and Operations at the Royal Devon and Exeter Healthcare NHS Trust.

I know that Sue and the new Board Members who have joined us are committed to meeting the challenging agenda now facing the Authority and to the work we are to do in organ donation, procurement and co-ordination. To be successful we will need the continued active support of many friends and colleagues - our own staff, those in the transplant community, the wider NHS, in Government and beyond. I am confident that such ready support will be forthcoming.

John Shaw CB, Chairman

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Further copies of the Bulletin can be obtained from the Information Executive at UK Transplant on 0117 975 7574

New SHA Members



Dr Chitra Bharucha MB BS FRCPath

Qualified in 1968 and worked in the Health and Social Services in Northern Ireland for over 25 years until she relinquished full time NHS duties in April 2000. She arrived in Northern Ireland from India in 1972 and has successfully combined family life with high level contribution in areas of Health, Arts, Education and Religion in Northern Ireland together

with national UK and international office. In 1981 she was appointed Deputy Director of the Northern Ireland Blood Transfusion Service and Consultant Haematologist in Belfast City Hospital where she treated patients with blood diseases.

She was Chairman of the UK Blood Transfusion Services, Standing Advisory Committee on Transfusion Transmitted Infections (SACTTI), and co-chairman of the International Society of Blood Transfusion (ISBT) Working Party on Cord Blood Banking; member of Council of the Royal College of Pathologists (RCPath) and Chairman of the Northern Ireland Affairs Committee of RCPath; member of Partners Council of the National Institute for Clinical Excellence (NICE) and member of the World Health Organisation (WHO) Expert Advisory Panel. She continues as a member of the Patient Liaison Group of RCPath. A significant success is the establishment of the Belfast Cord Blood Bank.

In 1999 she was invited by the National Blood Authority (NBA), to assist with the re-organisation of the English Blood Service from zonal to a centralised national structure.

Leisure interests include opera, classical music, hill walking, cycling and badminton.

Mrs Judith Mackay MBA

Mrs Judith Mackay is Head of Television and Multi-media Production at Aston University. Mrs Mackay brings extensive communication skills and a working knowledge of multi-media and information and communications technology to the Board, and has experience in both the commercial sector and, within the NHS, as Chairman of Northern Birmingham NHS Mental Health Trust. She has an interest in sport having served in various capacities on the Sports Council and the West Midlands Council for Sport and Recreation. Mrs Mackay's current post at Aston University involves working with Academic Schools to create multi-media packages for distance learners. Other interests include directing Birmingham International Film and Television Festival and serving as Vice Chairman of the Birmingham Repertory Foundation.

[This article has not been provided by Mrs Mackay who was not available when the Bulletin went to print. A further article will be provided for a future edition of the Bulletin.]



Neil Goodwin

Neil Goodwin has been Chief Executive of Manchester Health Authority since 1994 where he has led the development and implementation of strategies for improving health and health services. Previously, he was for six years the first Chief Executive of St Mary's Hospital NHS Trust, London and for three years before that General Manager of

Central Middlesex Hospital, London. He has also worked in a number of healthcare environments including mental health and learning disabilities.

Earlier this year Neil founded the Public Leadership Centre, which is based at the University of Manchester. The Centre provides leadership diagnosis and development and research services in collaboration with public service leaders and academics drawn from across England and Wales. Neil is an honorary fellow of two Manchester Universities and a graduate of London Business School; he researches and publishes on leadership and is in the throes of completing a PhD thesis on 'leadership and networks in health services'.

CHAIRMAN'S REPORT in summary

1999/2000 was dominated by two events: the Health Department's Quinquennial Review of UKTSSA and the investigation by the Department of Health Permanent Secretary into the circumstances whereby racist conditions were placed on an organ donation.

The Report of the Quinquennial Review of UKTSSA's operations and of transplantation more widely was published in February 2000. It concluded that UKTSSA is a good, effective organisation and that central organisation of the donation process is essential to maintain efficiency and ensure equity between those waiting for an organ. Also that the Authority, whose information and audit services formed a good basis from which to meet clinical governance requirements in transplantation, should continue as a Special Health Authority but be reconstituted and renamed **UK Transplant**.

Apart from the Authority's laboratory services, the Review recommended that all the present core functions should continue but with the addition of:

- new responsibility for working with hospitals across the country to identify ways of maximising organ donation and procurement rates;
- providing central support for co-ordinators (funding will be provided to support their employment locally in areas where none currently exists);
- closer involvement in developing national publicity initiatives;
- assisting in establishing a consultative forum as a focus for transplant issues and the development of policy.

These are exciting, if exacting, new challenges for the Authority to address. Early action to take these recommendations forward is clearly needed and is amply borne out by the fact that in 1999 the number of transplants undertaken fell from 2870 in the previous year to 2841, and the waiting list at 31 December rose from 6539 to 6716 over the same period.

Our task now is to implement these recommendations so that patients currently awaiting an organ transplant can look forward to everything possible being done to improve their prospects of receiving a transplant.

The Department of Health's report of the investigation into the conditional donation incident was published on the same day as the Review. The key findings were that

- (i) the recipients of the organs would have received them anyway. In practice, therefore, the racist condition had no effect;
- (ii) it is clearly abhorrent that organs should have been accepted on this basis;
- (iii) it is worrying that nobody thought to stop it.

Ministers confirmed that organs are donated altruistically and should go to patients in the greatest need. To attach any condition to a donation is, therefore, unacceptable.

UKTSSA welcomed the Panel's findings, its confirmation that no individuals were disadvantaged by the Authority's action and its clarification of the legal position around conditional donations. The Authority accepted that with the benefit of

continued on page 9

NETTING TRANSPLANT DATA*

... the Roadshow comes to you!

*Collecting transplant data - distributing statistics and analyses to the network of Transplant Units - using Internet technology

With so many new possibilities opening up through the use of Internet technology to access the new National Transplant Database, UK Transplant has decided to spread the word - throughout October the UK Transplant Roadshow 'Netting Transplant Data' will be touring the UK stopping off at 10 venues.

We hope to get representation from Regional Offices of the NHS Executive, Commissioning Health Authorities and from IT personnel in Trusts involved in transplantation as well as those staff and clinicians directly involved in patient care. In fact, anyone with an interest in how data and statistics on transplantation can be accessed on line, how to submit patient data on line, how to down-load onto a local system; the possibilities for future analysis - any which way - should attend.

The Roadshows have been planned to visit each NHS Region in mainland UK. If you can't make it to the one near you, you will be welcome at any of the others instead - see the locations below.

The programme which will be the same at each stop, is designed to encourage discussion and feedback on what is currently available and on what developments you would wish to see in future. This is your opportunity to say what you need or would like. There will be 'live' demonstrations of access to the database and chances for 'hands-on' practice.

Locations have been picked to be convenient for as many as possible within each Region and a buffet lunch will be provided to enable discussions to continue informally.

Invitations have been sent out and, as an additional reminder, posters have been sent to transplant Units. If these failed to reach you, please use the coupon below to reserve your place. Tell your colleagues - pass on the word - this is your chance to try your hand and see what is available to you on line direct.

We look forward to seeing you and explaining the new developments which are coming on stream fast.

David Shute
Director of Operations

THE PROGRAMME

Please feel free to join the programme at any of the breaks if you cannot be there for the whole morning.

- 9.30 Assemble and coffee.
-
- 10.00 Introduction and welcome.
-
- 10.10 Brief overview of the UKT information and statistics systems and service.
-
- 10.20 Demonstration and feedback discussion on:
- Patient Registration and Follow-up.
 - Downloading Data to your system.
-
- 11.00 Coffee Break and opportunity to try the system.
-
- 11.30 Demonstration and feedback discussion on:
- Using on-line statistics within Units.
 - Using Transplant Summary Statistics within the wider NHS.
-
- 12.00 Break and opportunity to try the system.
-
- 12.15 Parallel discussion groups led by UKT staff:
1. Future developments - discussing your needs and our ideas.
 2. Technical issues - bringing NTxD data on to your system.
-
- 12.45 Open session and questions on accessing information and other transplant issues.
-
- 13.15 Close and lunch with further opportunities for discussion and hands-on trials.

THE VENUES

10 venues and dates around the country have been selected - please choose the one most convenient for you - it does not have to be the one in your Region.

- October 3 **Scotland**
The Highland Hotel, Stirling
-
- October 4 **Northern & Yorkshire**
The Copthorne, Newcastle
-
- October 5 **Trent**
Risley Hall Hotel, Risley,
Nr. Nottingham
-
- October 10 **North West**
The Bridge Hotel, Prestbury
-
- October 11 **West Midlands**
The Copthorne Merry Hill, Dudley
-
- October 12 **Wales**
The Copthorne Hotel, Cardiff
-
- October 13 **South West**
The Shrubbery, Ilminster
-
- October 17 **Eastern**
Girton College, Cambridge
-
- October 18 **London**
The Thistle Victoria Hotel
-
- October 19 **South East**
Burford Bridge Hotel, Dorking

Details concerning the venues are still being finalised and may be subject to change. Information on how to get there will be sent to you personally, well ahead of the event.

Reservation

To assist our planning, please complete this form and return it to us - post free at
INFORMATION EXECUTIVE, UK Transplant, FREEPOST (SWB1474), Patchway, Bristol BS34 8ZZ

I would like to attend the Half Day Meeting on October at

I will/will not be able to stay for lunch

Please indicate any dietary requirements

Name (**BLOCK CAPITALS**)

Position

Unit/Hospital/Office

Postal Address

Postcode

Tel:

Fax:

(for acknowledgement of your reservation)

KIDNEY ADVISORY GROUP

To reflect the growing and strong links between kidney and pancreas transplantation, when they met on 24 May, the Kidney Advisory Group Members agreed that in future the Group would be known as the UK Transplant Kidney and Pancreas Advisory Group. Two new representatives were welcomed to the meeting: Mr Peter Lodge, from St James's University Hospital, Leeds, who replaced Mr Robert Johnson, from Manchester Royal Infirmary, and Ms Kate Darwin who attended as observer from the Department of Health.

Review of Renal Transplantation

Ms Darwin reported briefly on a study commissioned by the Department of Health to develop detailed service criteria for renal transplantation. The aim was to give the Regional Specialised Commissioning Groups the means to develop a configuration of services which would maximise clinical and cost effectiveness and, based on current provision and anticipated future developments, ensure equity of patient access. Members were informed that decisions about those units to be designated were expected to be finalised in 2001/2, following consultation with clinicians, the Royal Colleges, the Renal Association and patients' groups.

Changes to the National Kidney Allocation Scheme

Members reviewed discussion at the Renal Users' Meeting in January and endorsed the decisions made to give homozygous recipients priority for kidneys from homozygous donors, (though not over highly sensitised patients), and to offer the second kidney from adult donors to national favourably matched children before local favourably matched adults: both changes were implemented on 1 July 2000.

Paediatric Waiting Times

Following discussion at the BTS Congress in March, simulations had been carried out to assess the impact of extended waiting times on the allocation of HLA matched kidneys to children. The analysis showed that by extending the mean waiting time by an additional six months, 67% of children on the renal transplant waiting list could be offered a 000 or favourably matched kidney (rather than non-favourably matched as was currently the case), although 15% of children on the waiting list would still need to be considered for non-favourably matched grafts. Members agreed to share this information with colleagues in paediatric nephrology units.

Balance of Exchange

The Points Scoring Group had reconvened to consider ways in which the wide-ranging Balances of Exchange could be influenced. Simulations had indicated that major changes to the Kidney Allocation Scheme would be required to effect change and that local policies and practices were more likely to influence matters. Thus, no changes to the Balance of Exchange calculations or Points Scoring Scheme were considered appropriate. The Points Scoring Group was however, asked to consider ways in which young adults could be favoured when paediatric advantage ceases at 18 years.

En bloc Kidneys from Young Donors

Following acceptance in principle at the January 2000 Renal Directors' Meeting, Members agreed the implementation of a two year pilot scheme, effective from 1 September 2000, to transplant kidneys en bloc from donors under 5 years of age into adult recipients. Transplant Co-ordinators would be asked to seek permission for donation of these kidneys.

Kidney Damage

The disparity in kidney damage reporting levels between centres was highlighted. The report presented to

the Advisory Group has been sent to all Renal Transplant Unit Directors and an updated version to include re-grafts, transplant survival and the effect of donor age will be considered by Renal Directors in January 2001.

Perfusion Fluids

Mr John Forsythe had set up a study to assess the incidence of contamination of perfusion fluids. Oxford and Scotland had been the first areas studied; Guy's and the Royal London Hospital would follow. Early results had shown that in nine out of 39 cases organisms had been grown in perfusion fluid samples. Members looked forward to the completion of this unique study and its publication.

Pancreas Transplants

Increased pancreas transplant activity was noted and the suggestion made that when the annual number of kidney/pancreas transplants reached 50 it might be appropriate to review the allocation process. No changes would be made to the current arrangements until then. Members noted that the Scottish Executive had funded a kidney/pancreas transplant programme in Edinburgh and Glasgow.

Informed Consent

Dr Chris Dudley and Ms Kay Hamilton, from the Richard Bright Renal Unit in Bristol, had proposed a protocol for early identification of recipient consent to receive organs from marginal donors. Members felt that this subject warranted discussion in a wider forum; and it was therefore remitted to the Renal Directors' Meeting in January 2001. In the meantime, the Chairman has asked Directors of renal transplant units to review their patient information booklets.

Centre Effect

An encouraging report was received from the Centre Effect Task Force: initial analysis of renal transplants during 1994 to 1996 had demonstrated no significant difference between centres. The analysis would be updated for further consideration at the next Renal Directors' Meeting.

ISORY GROUPS

CORNEA ADVISORY GROUP

The main topic of discussion at the Cornea Advisory Group (CAG) on 27 June was the National Eye Retrieval Scheme. Since Members' meeting in December 1999, the CAG Reimbursement Scheme Task Force had as reported in the last issue of the UKTSSA Users' Bulletin, agreed the criteria for the establishment and funding of a local eye retrieval service in three pilot sites. Additionally, it was agreed that those centres which had contributed 100 corneas to the CTS in the previous 12 months, would receive a flat rate fee of £5,000. Only two centres (Moorfields Hospital and HM Stanley Hospital, St Asaph) were eligible for this payment in 1999/2000. All three pilot sites reported increased retrieval rates and were optimistic about the initiatives they had introduced to improve the day-to-day links between the eye retrieval service and local bereavement services. Members suggested that the Chairman make progress reports to the Department of Health with a view to obtaining increased ring-fenced funding for those centres that consistently achieve high cornea retrieval rates.

Reports from the Eye Banks

Although there had been a slight increase in the number of retrievals reported by some Eye Banks, others expressed disappointment with their retrieval rates. East Grinstead reported a 20% increase in the number of corneas issued compared with the previous six months whilst West Norwich were on target to increase their annual retrieval rate to a minimum of 400 corneas. The pilot scheme to improve retrieval rates within designated hospitals had formalised the relationship between the bereavement and eye retrieval services in Norwich and weekend cover was now available. A surprising fact to emerge was that 60% of deaths had been found to occur between Friday evening and Monday morning.

Surplus Corneas

Members were advised that for the first time in approximately two years there had been a small surplus of corneas in the CTS Eye Banks, which had made it possible to make offers of corneas to individual units. Any corneas which remained unused would next be offered to European countries. Corneas which had exceeded their storage date were destroyed unless they were suitable for further processing and storage for use in split lamellar grafts.

Donor Information

Members reaffirmed the importance of the information requested on the Ocular Tissue Donor Information Form: this should be provided for all eyes sent to the Eye Banks since it enabled assurances to be given regarding the safety of corneas issued. The Duty Office were asked to monitor compliance and report back to Members.

Cornea Audit Sub Group

Earlier in the day the Cornea Audit Sub Group had considered analyses of factors affecting one-year cornea graft survival and centre specific information for corneas supplied to the CTS Eye Banks. No significant trends had been identified for one-year cornea graft survival and further analysis would include two or three year outcome and factors relating to centre size. Members were particularly interested to note the centre specific summary information which gave an indication of those centres which had provided a high proportion of corneas suitable for PKP grafts. Further analysis was to be undertaken to consider donor age and time from death to enucleation. Members thought it would be helpful for the data to be circulated in an anonymised format once the additional analysis had been completed. The Cornea Audit Sub Group also discussed the benefits of future analyses including the assessment of vision and how this was achieved post transplant. Other factors affecting the recipient, such as pain, were

considered to be of equal importance and Members of the Advisory Group asked for recommendations regarding the optimum periods for future follow-up.

Ocular Tissue Standards and Audit Group

OTSAG had also met earlier in the day and discussed how to detect previous refractive surgery when screening donors since this was not immediately obvious in the cornea. Although technical equipment could be used Members favoured the proactive collection of donor information from relatives. Use of single corneas for more than one recipient was considered inappropriate; it was agreed that the rules agreed by the Cornea Advisory Group relating to single use for sclera should apply equally to corneas to minimise potential risks of disease transmission.

OTSAG had also considered a consent form with information for relatives of potential donors and an information leaflet for patients referred for cornea transplantation: both would be submitted for inclusion on the Royal College of Ophthalmologists' Website.

Department of Health Code of Practice for Tissue Banking

Members welcomed the Code of Practice which had been agreed by Ministers and released for consultation. Tissue Banks would be required to agree standards with providers of tissue and the document would form the basis for the inspection and accreditation of tissue banks by the Medicines Controls Agency.

Laraine Joy
Head of Advisory Group Executive

UK RENAL REGISTRY

The UK Renal Registry is part of the pioneering work of the Renal Association in support of clinical governance. The primary intention of the UK Renal Registry is accurately to monitor the quantity and quality of renal care in the UK, and thus to improve the quality and efficiency of this care. An annual report is provided by the Registry to all providers and purchasers of renal services, to facilitate that process. This report is also available on the Registry's website (www.renalreg.com). The Registry data will enable internal audit within renal centres, support comparative audit, and provide information to stimulate and inform the process of improving protocols of care.

Much of the work of the Registry is based on the Renal Association document on "recommended standards and audit measures for the treatment of adults with renal failure". The work of the Registry is essential for monitoring attainment of those standards and closing the audit loop.

The Renal Registry committee includes, in addition to nephrologists from the Renal Association, Mr S Sadek and Dr W Wong appointed by The British Transplantation Society. Other members include representatives from the Department of Health, the Association of Clinical Biochemists, Health Commissioners and the National Kidney Patient Federation.

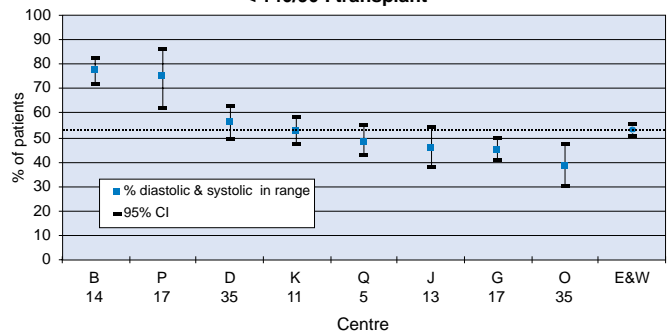
The 1999 report included data from renal units covering 43% of the UK adult population. Since then many more centres have joined. In the 214 page Registry report, national trends and differences between units were highlighted. Demographic analysis included patterns of care, geographical inequalities in access, diagnosis and age distribution. There was information on indicators of quality of care such as haemoglobin, dialysis adequacy, blood pressure, phosphate and cholesterol. Performance in relation to the Standards document was assessed and there was a paediatric chapter and a chapter on international comparisons.

Although the 1999 Registry report concentrated mainly on dialysis care, chapter 11 related to transplantation. This chapter highlighted the disparities between centres e.g. in the percentage of patients aged less than 65 with a functioning transplant and the percentage who have ever been transplanted. The reasons for this are not yet known (see Figure 1).

Whilst UK Transplant has donor/recipient transplant data that the UK Renal Registry does not collect, the Registry does collect quarterly sequential data on transplant patients including blood pressure, cholesterol and renal function. Analysis showed that despite the high death rate from cardiovascular disease, control of blood pressure and cholesterol in transplant patients appears

Figure 2

Percentage of patients age < 60 with BP < 140/90 : transplant



to be poor, with significant differences between centres. In Figure 2, the numbers below the centre codes on the graph indicate the percentage of missing data from each centre.

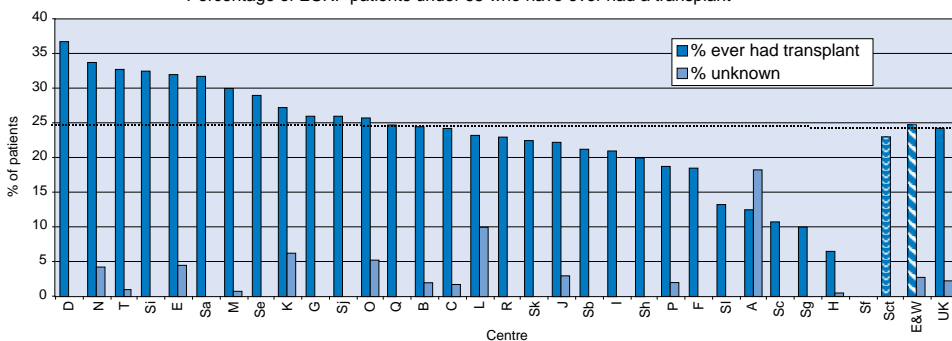
Also not held by UK Transplant, is the information for comparison with the overall renal replacement population, pre-transplant history, or subsequent events after transplant failure. It is hoped that the two Registries may be able to work together to produce a unique analysis through combining this data.

UK Transplant and the Registry are currently collaborating to audit the waiting list data in relation to the total renal replacement therapy population.

David Ansell
 Director of the Renal Registry
 Tel: 0117 959 5666

Figure 1

Percentage of ESRF patients under 65 who have ever had a transplant



TalkShop

THE THIRD TRANSPLANT TALKSHOP

The third Transplant TalkShop, this time in the South Thames area, was held on 23 May at the Spa Hotel, in Royal Tunbridge Wells. Delegates enjoyed the venue (which provided a welcome change from London-based gatherings), and found discussions and presentations both stimulating and thought-provoking.

Dr Douglas Briggs, Chairman of the TalkShop project, introduced the day.

Mr Zafar Chawdhery, Consultant Transplant Surgeon, at St Helier Hospital, introduced the 'Regional' session. A regional overview was provided by Ms Helen Mandfield, Transplant/Procurement Service Manager at South Thames Transplant Co-ordination Service, outlining unique local initiatives such as an In House Co-ordinator pilot scheme at King's College Hospital and an ethnic minority community education programme which would be running in the London area, by the end of the year.

Next, Mr Nigel Heaton, Consultant Transplant Surgeon at King's College Hospital, provided a fascinating insight into the world of liver lobe and living donor transplants. Mr John Taylor's (Consultant Transplant Surgeon, Guy's and St Thomas' Hospital) presentation, highlighted the benefits of pancreatic transplantation in improving diabetic patients' quality of life.

The second session introduced the topics for later discussion in seminar groups. Ms Lisa Burnapp, Senior Nurse/Living Donor Co-ordinator, Guy's and St Thomas' Hospital, showed the steady growth in living kidney donor transplants in South Thames which account for 28% of the total kidney transplants performed. Dr Simon Cottam, a Consultant Anaesthetist from King's College Hospital spoke on the subject of 'Donor Selection and Management'. Ms Marie Cummins, Transplant Co-ordinator introduced the issue of 'Consent and Counselling for Donor Families' and was joined by Ms Caroline Bunker a donor mother who bravely relived her and her family's experiences following the death of her son and their decision to donate his

organs. The session ended with Mr René Chang from St George's Hospital, recounting his unit's experience of conducting a Non Heart Beating Donor Programme.

The seminar group discussions proved, yet again, to be useful opportunities for sharing experiences, widening understanding and increasing knowledge.

The next TalkShop is to be held in the West Midlands region, at the National Motorcycle Museum on 3 November. It is hoped that Lord Hunt, the Government Minister with responsibility for Transplantation policy will open the day.

Other regions interested in hosting a Transplant TalkShop should contact Kate Wyatt.

Kate Wyatt
Corporate Affairs &
Administration Division
UK Transplant
0117 975 7566



Mr Nigel Heaton - insight into Liver Lobe and Living Donor Transplants

CHAIRMAN'S REPORT

(from page 2)

hindsight, its senior management would have acted differently, and welcomed the report's recommendations that the rôle and responsibilities of the Authority should be clarified.

As last year, waiting for publication of the Quinquennial Review Report on the future of the Authority has, of necessity, limited innovative work. Nevertheless our Report describes a busy year for the Authority. We developed proposals for Zonal Organ Retrieval Partnerships, and for additional ways of capitalising on the investment in the new National Transplant Database. Special Health Authority Members took the opportunity to develop their own views on ways in which organ donation and procurement might be improved. The resultant discussion paper*, sent to the Minister of State for Health in March, concluded that a wide range of measures is needed by a wide range of agencies to address the complex and highly emotive issue of meeting the current organ donor shortage.

Our Report discusses the huge amount of work undertaken by our staff during the year. It is a great tribute to their commitment and loyalty that so much has been achieved during the year and that they have maintained their morale and good humour during a year of turbulence and uncertainty. I am profoundly grateful to each and every one of them.

Throughout, the Authority's work was supported by the National Transplant Database and we always bear in mind that it is individual members of the transplant community to whom we are indebted for the data it contains. The Database is used extensively by our Advisory Groups whose contribution to the development of protocols and procedures underpins all our activities. The Special Health Authority is extremely grateful both to the transplant community for the data they provide and to the members of our Advisory Groups and their growing list of Task Forces and Registers.

The Board of the new UK Transplant will, I know, be keen to build on the excellent work already undertaken by those who have served UKTSSA and its predecessors so well.

* "Options for Improving Organ Donation" (copies available from UK Transplant)

OXFORD TRANSPLANT CENTRE: 25TH ANNIVERSARY

SATURDAY 3 JUNE 2000

The Year 2000 marked the 25th anniversary of the first Oxford kidney transplant. Professor Sir Peter Morris performed the first two kidney transplants in Oxford in January 1975. The second of those transplants is still working well, after 25 years, and the recipient, Alan Newey, says that his kidney has thrived on a menu of beer and curries. Since 1975, we have performed over 1,700 kidney transplants in Oxford.

Approximately 900 of these continue to function well, thus ensuring good quality lives for these recipients.

We felt that the 25th anniversary was an ideal opportunity to arrange a large celebration so that we could promote the donor card and donor register and also raise the profile of transplantation to remind everyone that transplants do save lives and improve the quality of life for many people.

We also wanted to make this a joyous occasion in order to thank the donor families, transplant recipients and all the clinical teams who had contributed to the building of the successful Oxford Transplant Service.

The day of the celebration dawned bright and clear and the rain that we had been dreading did not appear. A marquee was erected on the lawn outside the Transplant Centre and we prepared for a balloon launch of some 600 balloons. We wanted each transplant patient to release a balloon, in memory of their donor, and we also gave special balloons to the living donors who joined in the celebration.

We were expecting approximately 650 patients and their families and by 1.30 p.m. the visitors started to arrive. There were poster displays for them to enjoy covering aspects of tissue typing, transplant research and the past successes of the transplant programme with future hopes and plans. Also, there were refreshments, various raffles and stalls and face painting for the children. Star attractions included two transplant surgeons, a health care assistant and an administrator, dressed as Teletubbies and the launch of the



Professor Sir Peter Morris and Mr Alan Newey, Oxford's longest surviving kidney transplant patient - Kidney 25 years old

balloons, with a background of fireworks. Very impressive sight and sound! Speeches followed the balloon launch with Professor Sir Peter Morris speaking about the development of transplantation in Oxford and Professor Peter Friend looking ahead to future plans with the launch of a fundraising campaign to support new facilities for patients and research staff.

Following the speeches, the Teletubbies, to the sound of a magnificent drum roll from transplant patient Chris Denham and his band, carried in the giant birthday cake and everyone enjoyed champagne and cake.

Did the celebration fulfil our aims? Feedback from patients and their families tell us that it was certainly a joyous occasion. Also, a marvellous opportunity to meet other patients, friends and staff.

The staff also enjoyed themselves and gained an enormous sense of pride from seeing so many patients enjoying their lives.

Most importantly, the media reaction was very positive, and resulted in eight subsequent newspaper articles, three television and three radio interviews. Thus, the messages 'carry the donor card and inform your family of your wishes' and 'transplants save lives' were very high profile throughout our donor region and nationally as a result of two articles in the national press. We believe that such positive publicity will help the donor and transplant programmes in the future.

Grateful thanks to the following groups for making this celebration possible:

Gloucester Kidney Patients Association, Six Counties Kidney Patients Association, Novartis Pharmaceuticals Roche Pharmaceuticals, Wyeth Pharmaceuticals, Fujisawa Pharmaceuticals, individual patients for attending, speaking to the press and for their private donations.

(Since the celebration we have been approached by environmental groups to say that balloon launches are not environmentally friendly! We will have to think of some other form of celebration in the future!)

Patricia M Franklin
Clinical Nurse Specialist &
Psychologist in Transplantation



Doctors Inigo Lopes and Vish Anand, Health Care Assistant Kelly Holland, Barney Perkins Administrator, dressed in Teletubbie outfits

THE FIRST THREE MONTHS

It seems only yesterday that, after several late nights and copious volumes of a well-known treatment for greying hair I was able to invite John Shaw, the Chairman of the Special Health Authority, to launch the site. But it has now been active for three months! Whilst we are indebted to Mark Walker and his team at Webselect for their expertise in producing the website and supporting it through hatching and infancy, our thoughts are turning to solo flight!

Regular visitors to the Website will have spotted that transplant statistics for the current year are updated on a daily basis. Additionally, electronic copies of new Authority publications are incorporated into the website as soon as possible after publication, but to make this process even faster we will be taking over these website editorial tasks in-house.

Other new tasks for us will include a wide range - from making amendments arising from the Authority's change of name and adoption of the NHS Style to the development of new pages and links. One such link will be to the NHS Organ Donor Register website which was itself launched on 1 August 2000, the URL being www.nhs.uk/organdonor (see Webwatch below).

To date we have received positive feedback about the Authority website but have no intention of resting on our laurels. We regularly monitor patterns of use. Suggestions or comments are always welcome and should be addressed to me.

Trevor Jones

Webmaster, Information Executive, UK Transplant
0117 975 7574

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Web Watch ...

The first of an occasional series describing websites potentially of interest to those involved in transplant-related services.

The NHS Organ Donor Register website
URL notified: www.nhs.uk/organdonor
alternative URL(s): www.nhsorgandonor.net

Launched on 1 August alongside the latest NHS initiative to boost the number of registrations to the NHS Organ Donor Register (ODR) and to increase public awareness of the issues involved in transplantation.

The developers have provided the option of a text only site in addition to the html-based version in the usual ODR red, white and blue colour scheme. The opportunity has been taken to re-brand the literature line as the Organ Donor Information Line while emphasising that operators cannot provide advice or support.

The site has seven major sections:

"The Facts" - basic information on the need for transplants;

"Success stories" - one 34-year-old donor, one 70-year-old recipient;

"Families and Friends" - emphasises the need for registrants to inform relatives of their wishes;

"What your organs do" - useful information on the role of various organs. Specific pages deal with kidney, liver, heart, lung, pancreas and small bowel and cornea. Although the graphics still need sorting out, this section does contain some useful links to other organisations.

"The Asian Community" - discusses the particular issues facing the community;

"Your Questions Answered" - uses UK Transplant's Questions and Straight Answers booklet.

Later pages carry a link, which encourages the visitor to consider the topic of tissue donation, especially in situations where solid organ donation does not prove possible.

In summary, once the teething problems are ironed out, this site will be a useful foil to the UK Transplant site. Intratext hyperlinks which enable visitors to go straight to the information required would be beneficial and will be the strategy used by the UKT Webmaster when finally positioning links from the UK Transplant site.

Trevor Jones

Webmaster

Information Executive
UK Transplant

ASDA GREAT NORTH MILLENNIUM TRANSPLANT GAMES

The 23rd British Transplant Games were held at the end of July on Tyneside. This is the third time that Ross Taylor and the local organising committee (consisting of transplant professionals and Transplantees from the Freeman and the Royal Victoria Infirmary), have run the games, with their experience, dedication and enthusiasm contributing to a highly successful weekend.

The Lord Mayor of Newcastle opened the games with two Birmingham athletes presenting the torch to two Newcastle athletes. This was followed by the athletes oath being read by Leanne McKee from the Freeman, the first live lobe lung transplant competitor at these Games.

The sporting events included the usual track and field, racket sports, bowls, swimming, canoeing and cycling with some extra events to celebrate the Gift of Life - fishing, sailing, archery and driving skills. The children's sporting and social programme were held separately from the adults, and organised by Jean Sharp.

Many of the competitors would not be here today without their life saving transplants and they advertise the benefits as well as promoting an awareness of the desperate need for more donors. The level of competition is high and the British Team for the World Games in Japan will be selected from the winners on Tyneside.

However, all 700 competitors are winners in their fight for life. One thousand voices nearly lifted the roof off the Telewest Arena at the Gala dinner as they all joined hands to sing their song - "You'll never walk alone".

Lynne Holt
Local Organising Committee
Heart/Lung Transplant Co-ordinator
Freeman Hospital

ORGAN DONOR REGISTER NEWS

The Department of Health's campaign to boost public awareness of the need for organ donation has received tremendous support from the media and major companies and organisations over the past year.

Health Minister Lord Hunt helped launch the latest initiative, a scheme developed jointly by the Department of Health and Boots The Chemists that will make it easy for many more people to become donors. Customers with the store's in-house loyalty 'Advantage' card and those applying for one can now join the Organ Donor Register by simply ticking a box on the application form. Boots is investing £500,000 in the scheme and promoting it in its stores and its magazine. With 12 million current Advantage Cardholders and new applicants running at 30,000 a week, the potential is enormous.

Lord Hunt said he was grateful to Boots for what was an imaginative and public-spirited idea. "In the past year we have already increased the register by over a million. It would be marvellous if we could add another million as a result of this initiative."

Backing has also come from the mass circulation *Sun* newspaper, which recently put its weight behind publicising the shortage of transplant organs. The paper's involvement was triggered by the story of Sally Slater, who had a heart transplant operation in April. Readers were encouraged to fill in a special donor form printed in the paper and to join the Organ Donor Register.

Television has also played its part. In the build-up to the Millennium, ITV companies launched the 'Year of the Promise', encouraging viewers to call in with a promise that was a positive step for them and for others. HTV and Meridian both chose to support organ donation and viewers were told how to join the register.

This was followed up with a 'Year of the Promise' day over the May bank holiday weekend. Viewers saw interviews with transplant recipients and donor families and heard about the importance of carrying a donor card, and telling friends and family of one's wishes, while the cast of the hugely popular *Coronation Street* came out in support of the campaign.

In the meantime, the Department of Health's work in the area goes on. Specialist transplant co-ordinators and a South Asian communications agency are helping to raise awareness within the South Asian community and a special leaflet is available in English, Urdu, Gujarati, Hindi, Punjabi and Bengali.

In March, the Department supported the first-ever Multi-Faith Conference, when people from all faiths had the chance to debate important issues about donation. The Department continues to work with patients' groups and other voluntary organisations concerned with transplantation. The groups include the particularly successful organisers of the National Transplant Games and TIME, the organisers of National Transplant Week, both events created a lot of good publicity.

The Department's most recent initiative came on-stream, or rather on-line, in August with the launch of the organ donor website. Aimed at the public and healthcare professionals alike, the site contains a wide range of information about organ donation and transplantation. People can also download a donor card and join the donor register on-line.

The site can be found at: www.nhs.uk/organdonor

Elizabeth Dawes
Publicity Manager
Department of Health

Transplant Statistics

1 January 2000 to
30 June 2000

Active = Active patients
Sus = Patients temporarily suspended

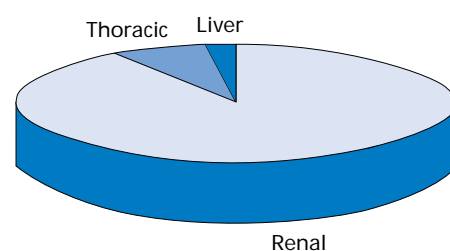
These statistics are provisional and subject to some modification (mainly due to belated notifications). Comparisons are given with activity during the same period (January to June) in 1999. Percentage changes are given when the activity rate is at least 10.

The number of donors reported in 2000 was 422 compared with 385 in 1999.

National Transplant Waiting List at 30 June 2000

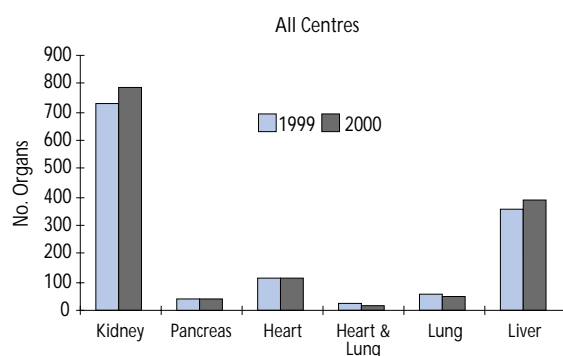
Organ	UK			Republic of Ireland			All Centres
	Active	Sus	Total	Active	Sus	Total	Total
Kidney	4715	1134	5849	0	143	143 *	5992
Kidney & Pancreas	60	26	86	0	12	12 *	98
Pancreas	7	7	14	0	2	2 *	16
Heart	157	14	171	22	0	22	193
Heart & Lung	94	5	99	2	0	2	101
Lung	161	5	166	0	0	0	166
Liver	122	6	128	19	0	19	147
Total Waiting	5316	1192	6513	43	157	200	6713

* Republic of Ireland operates its own Kidney allocation scheme



Cadaveric solid organ donors reported to UKTSSA classified by organs donated

Organ	UK			Republic of Ireland		
	1999	2000	%change	1999	2000	%change
Kidney	658	727	10	68	58	-15
Pancreas	38	41	8	2	1	-
Heart	105	102	-3	10	12	20
Heart & Lung	19	15	-21	2	0	-
Lung	50	41	-18	3	5	-
Liver	323	360	11	35	31	-11
Total Organs	1193	1286	8	120	107	-11
Total Donors	349	390	12	36	32	-11



Transplants performed in the UK and Republic of Ireland as reported to UKTSSA

Organ	UK			Republic of Ireland			Total		
	1999	2000	%change	1999	2000	%change	1999	2000	%change
Cadaveric Kidney	623	676	9	59	57	-3	682	733	7
Live Kidney	124	140	13	1	0	-	125	140	12
Kidney & Pancreas	12	11	-8	2	2	-	14	13	-7
Pancreas	3	1	-	0	0	-	3	1	-
Cadaveric Heart	105	106	1	2	5	-	107	111	4
Domino Heart	9	6	-	0	0	-	9	6	-
Heart & Lung	21	14	-33	0	0	-	21	14	-33
Lung	47	40	-15	0	0	-	47	40	-15
Live Lung	4	0	-	0	0	-	4	0	-
Liver / Liver Lobe	321	338	5	15	18	20	336	356	6
Live Liver / Liver Lobe	6	3	-	0	0	-	6	3	-
Total Solid Organ Tx	1275	1336	5	79	82	4	1354	1417	5

Conference diary

2000

World Congress of High-Tech Medicine, During the World Exhibition 2000

15-20 October, Hanover, Germany

8th International Congress on Ethics in Medicine

5-9 November, Beer Sheva, Israel

Information: Congress Secretariat,
Peltours-Te'um Congress Organisers,
POB 52047, Jerusalem 91520, Israel

Tel: +972 2 648 1245

Fax: +972 2 648 1305

E-mail: teumcong@netmedia.net.il

Website: www.teumcong.co.il

2001

Renal Transplant Directors' Meeting

Tuesday 23 January 2001

Information: Royal College of
Physicians, London

Invitations will be extended to Directors
of Renal Transplant Units, Heads of
Tissue Typing Laboratories and an
additional nominee from each
transplant centre.

Fourth Annual Congress of the British Transplantation Society

27-29 March, Academic Centre of the
John Radcliffe Hospital, Oxford

Information: Catriona Sanderson, BTS
Secretariat, Triangle House, Broomhill
Road, London SW18 4HX

Tel: 020 8875 2430

Fax: 020 8875 2422

E-mail: secretariat@bts.org.uk

10th Congress of the European Society for Organ Transplantation

6-11 October, Lisboa, Portugal

Information: Certame Tv.do Forte De
S.Pedro, 1 2780-600 Paco de Arcos,
Portugal

Tel: +35 11 440 6200

Fax: +35 11 440 6209

2nd International Congress on Immunosuppression

6-8 December, San Diego, USA

Information: Kimberley Zafetz,
Professional Postgraduate Services®,
PO Box 1505, Secaucus, NJ 07096-
1505, USA

Tel: +201 271 6142

Fax: +201 617 7546

Website: www.ppscme.org/ici

NOTICES

ALISON CROMBIE

*In the last issue Alison Crombie was given
the wrong affiliation. For this we apologise.
Alison is on secondment from the North
Thames Transplant Co-ordinating Team and
is currently a research fellow at the Centre
for the Study of Health, Sickness and
Disablement at Brunel University, where she
is completing a PhD on the social and
cultural factors in living kidney donation.*

ORGAN RETRIEVAL WORKSHOP

UK Transplant will be facilitating the
fourth Organ Retrieval Workshop to be
held at the Royal College of Surgeons in
London on Thursday 16 and Friday 17
November 2000.

The Workshop has been extended to 1½
days to meet comments made from
attendees at earlier events then more time
was needed to do justice to this important
topic. Further details, application forms and
the Workshop programme can be obtained
from the Advisory Group Executive at UK
Transplant - 0117 975 7516.

Laraine Joy
Advisory Group Executive

NINTH ANNUAL REPORT

*The Full Report of the Special Health
Authority describing the work of
UKTSSA's year - Ninth Annual Report and
Accounts: April 1999 - March 2000 - and
its companion volume - Transplant Activity
1999 - may be obtained from the
Information Executive, UK Transplant
(Telephone 0117 975 7574)*

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NHS

UK Transplant

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UK Transplant Emergency Contact Telephone Number

In the event of the main UK
Transplant system failing, there is
an alternative telephone number
that can be used - 0117 931 4777.
During office hours this number will
be answered by the UK Transplant
Receptionist but out of hours the
number is automatically directed
to the Duty Office.

0117 931 4777 should only be
used if you are unable to obtain
a response from the 0117 975
7575 telephone number.

VOICE RECORDER

TELEPHONE CALLS
TO THE UK TRANSPLANT
DUTY OFFICE

This notice is to inform users that
all telephone calls to the Duty Office
are recorded. OfTel have agreed
that this statement is an appropriate
safeguard permitting the recording
warn tone to be suppressed.