

First Impressions



- our new Chief Executive takes stock

It was my privilege to be given the opportunity to visit a large number of the country's transplant units during my first four weeks at UKT. My visits

gave me a comprehensive look at life in transplantation in action and I am grateful to everyone for making them so worthwhile.

My initial impressions are as follows:

Transplantation at its best relies on a multidisciplinary team approach with each and every participant being valued for their own important contribution.

Staff in the transplant community are incredibly enthusiastic, committed and hardworking. However, in some areas at least, there could perhaps be rather more recognition and support from the local NHS.

An increase in organ procurement is desired, essential and, I think, achievable, but will need to be supported by improvements to the infrastructure such as increased numbers of ICU beds and medical and procurement staff.

There is unanimity of opinion and enthusiasm for increasing the number of transplant co-ordinators and ensuring that they are structured, co-ordinated and supported more appropriately.

There is an abundance of pioneering spirit and the enthusiastic development of innovative clinical protocols such as the use of non-heart beating donors, living related donors and laparoscopic kidney retrieval. Extending the use of these and other initiatives will be crucial if the number of organs is to increase.

UKT is a highly regarded organisation and must continue to work closely with doctors, scientists and nurses to ensure that it continues to function effectively and to the highest possible standard of quality.

Overall, I found a great enthusiasm and willingness to support the recommendations made by the Quinquennial Review and a readiness to participate in and support the changes that are required.

I was very much heartened by the strong sense of purpose shared by all those whom I met and the excellent collaboration between UKT and the transplantation service in the NHS. I know that if we can harness the energy and enthusiasm, which abounds, the future of transplantation will be very exciting indeed. I am keen to ensure that changes introduced have a beneficial impact on the quality of life of individual patients and their families and, rightly, afford all of us pleasure and a degree of pride in knowing that we have all contributed to a lesser or greater degree.

Mrs Sue Sutherland
Chief Executive

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Further copies of the Bulletin are available from the Information Executive at UK Transplant on 0117 975 7574

THE FOURTH TRANSPLANT

TalkShop

WEST MIDLANDS REGION

The Fourth Transplant TalkShop, covering the West Midlands Region, was held in Birmingham at the National Motorcycle Museum on 3 November. The TalkShop was organised jointly by UK Transplant, the Procurement Co-ordinators from the Queen Elizabeth Hospital Birmingham (QEH) and Beverley Cornforth (Transplant Educationalist) to bring together purchasers, providers, chief executives and those working within transplantation. It provided an excellent forum to discuss current problems and possible solutions.

The day was introduced by Mr John Shaw (Chairman of UK Transplant). Mrs Sue Sutherland (Chief Executive, UK Transplant) then gave an interesting insight into how UK Transplant and the Department of

Health will be working together to meet the challenge of re-organising transplant services within the UK.

Dr Douglas Briggs, Chairman of the TalkShop project, gave the audience an overview of donor numbers nationally, and Professor Paul McMaster (Consultant Hepatobiliary Surgeon, QEH) focused on the particular problems within the West Midlands, which currently has the lowest donation rates in the country at 8.6 pmp. Jane Eminson (Regional Specialised Services Group), introduced her team and explained how services are commissioned.

The first session "Implications for ITU" was presented jointly by medical staff and the Procurement Transplant Co-ordinators from QEH. Dr Tom Heafield (Consultant Neurologist, QEH), discussed the reasons why doctors may find it

difficult to approach bereaved families to request organ donation, and highlighted some of the problems associated with the diagnosis of brain stem death. He recommended that all doctors carrying out brain stem death tests should hold a local or nationally recognised qualification. Dr Dave Rosser (ITU Consultant, QEH), went on to highlight the difficult decisions clinicians face on a daily basis when deciding which patients to admit into scarce ITU beds. Like several of the speakers, Dr Rosser raised the concern that the United Kingdom falls a long way behind many other European countries in the provision of ITU beds and resources.

Jo Hardy (Donor Action Project Manager), presented data which had been collected from the Region within the last six months, as part of the Donor Action project. One of the most important findings was that the West Midlands has a 52% donor family refusal rate, which obviously contributes to the poor donation rates seen within the Region. Mr Antony Hooker (Regional Procurement Transplant Co-ordinator, QEH) described how the Transplant Co-ordinators are intending to pilot

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Informal discussions are welcomed by the Chief Executive, Sue Sutherland by telephoning 0117 975 7500

Information packs and further information are available by telephoning the Personnel Office on 0117 975 7469

Closing Date:
15 Dec 2000

The selection process will take place in Bristol during January 2001

MEDICAL DIRECTOR

Salary will be in accordance with nationally determined consultant pay scales

UK Transplant is a Special Health Authority with responsibility for providing support to transplantation services across the United Kingdom.

A recently published Quinquennial Review recommended that UK Transplant take on a number of additional responsibilities including improving organ donation and procurement rates across the UK.

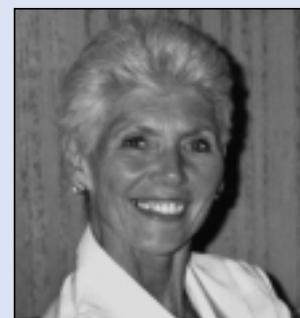
As an Executive Director of the Authority, accountable to the Chief Executive, the Medical Director will make a significant contribution to ensuring that these new challenges are met.

Potential candidates will have a thorough understanding of transplantation issues, demonstrable leadership skills and the ability to command respect and build effective relationships with senior doctors in Transplantation, Trusts, Health Authorities and Regional Offices.

FOX DEN ROAD, STOKE GIFFORD, BRISTOL BS34 8RR
www.uktransplant.org.uk

IN OUR LAST BULLETIN ...

We were unable to include a picture of one of our new SHA Board members, Mrs Judith Mackay....



TalkShop

"Required Referral" and "Collaborative Requesting" schemes in the University Hospital Birmingham Trust. The pilot studies will mean that all impending and actual neurological deaths are referred directly to the transplant co-ordinators, so that donation potential can be assessed. Then when any potential organ donor is identified, the co-ordinator will go along to the referring hospital to make the request for organ donation in collaboration with the ITU clinician. It is hoped that a joint approach will have a positive effect on donation rates within the region.

The afternoon sessions focused on ways to overcome donor shortage, and started with a session by Dr Andrew Stein (Consultant Nephrologist, Walsgrave Hospital). Dr Stein presented some controversial ideas relating to paying transplant co-ordinators for each donor they identified on ITU, and payment to individuals willing to be living kidney donors. Mr John Buckels (Consultant Transplant Surgeon, QEH) talked about the pros and cons of living liver donation. QEH already has a well-established liver splitting programme, which has helped to maintain the number of liver transplants performed at the hospital annually despite the continuing fall in donor numbers.

Mrs Pam Buckley (Transplant Co-ordinator, Newcastle) introduced the final session of the day. Pam gave an excellent insight into how non heart beating kidney donation was introduced in Newcastle, and highlighted the difficulties she faced when first establishing the programme. The successful combination of Newcastle's cadaveric and non heart beating programme means they have the highest donation rate per million population in the country. Mr Nick West (Transplant Co-ordinator, Coventry) reiterated the problems he has faced

trying to establish a non heart beating programme in his region.

It is hoped that the proposals presented to the TalkShop audience will be moved forward, and that the West Midlands region will begin to see an improvement in donation rates as a result.

Susan Richards
Regional Procurement
Transplant Co-ordinator
Queen Elizabeth Hospital,
Birmingham

"It is a collaborative responsibility and presumably there will be a collaborative solution"

We at UK Transplant were delighted with the collaboration generated by the speakers and delegates at the West Midlands TalkShop. It achieved its intended aim of drawing commissioners, providers and members of the transplant community together, to challenge previously held beliefs about the funding and organisation of organ procurement and to develop a future partnership. The message throughout the day, from all speakers, was one of co-operating to create a unified regional - and also national - strategy for increasing organ donation. For those of you who were not present on the day, a selection of pertinent quotations from the speakers should help to give a flavour of the proceedings. Professor McMaster commented, "I do hope this won't just be a TalkShop, but I hope we'll come away from it with some concrete proposals that purchasers, chief executives and others in the field can follow."

Sue Sutherland also emphasised the collaboration that is currently undertaken by surgeons such as Bob Bonser and co-ordinators (Sharon Beer, Caroline Stanton and Mark



*West Midlands Transplant Talkshop Organising Team.
From left to right: Bev Cornforth, Antony Hooker, Susan Richards,
Kate Wyatt, Dr Nick Richards*

Gordon) who are involved in UKT's Advisory Groups, "This is an excellent example of individuals and organisations that are prepared to work together, not just for the benefit of their own local patients, but for the benefit of patients across the whole of the United Kingdom." This partnership is fundamental to the future development of a UK-wide transplant service.

Dr Peter Doyle, from the Department of Health, made the following statement:

"Lord Hunt...has given a commitment in principle as you know, not only to the development in UKT that Sue was talking about earlier, but what is called the 'whole hospital approach' which is based on an adaptation of the Spanish model, but is integrated on a much wider sense with the whole dying process...on identifying all people dying in hospital, looking to their needs, ascertaining their wishes and that will include wishes in respect of organ donation."

Dr Briggs summed up the future approach for all regions that are hoping to increase organ donation:

"I think one thing which is crucially important is to remember that every unit in every region is different and ... we have to learn to react to the particular circumstances in a particular unit, or part of the country by the initiative which is most suitable to that and think of all these

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Members of both the Cardiothoracic and Liver Advisory Groups welcomed the revised guidelines from the Advisory Committee on the Microbiological Safety of Blood and Tissues for Transplantation (MSBT).

At both meetings, Members noted that in August the UK Transplant Advisory Group Chairmen had agreed that patients requiring multiple organ transplants should be registered on one waiting list only and flagged to indicate the multiple organ requirement. Patients would be registered according to the priority organ – that on which they were clinically dependent and it would be for the transplant unit to register such patients as super urgent for a liver or urgent for a heart, if appropriate. If not so designated, the patient would not take priority over others on the waiting list and offers of organs would continue to be made to liver transplant and cardiothoracic units in line with the normal offering sequence. Liver and cardiothoracic units would continue to take the initiative to negotiate retrieval of the kidney for their patient in such cases.

Members of both Groups were reminded of the importance of completing Core Donor Data and Organ Specific Forms and providing clear copies to accompany donor organs and for UK Transplant. Organ Specific Forms now serve as the Human Organ Transplant Register (HOT) Form A, without which organ retrieval is illegal.

CARDIOTHORACIC ADVISORY GROUP

Registration of Patients for Cardiothoracic Transplants

At the Cardiothoracic Advisory Group meeting on 26 September, Unit Directors were encouraged to review patients who were registered on the national transplant waiting list but not actively so (suspended patients). Members were also reminded of the

criteria for registration of small adults: 16 years or over and with a body weight over 30 kg and up to 40 kg.

Members discussed the registration of urgent patients to receive blood group incompatible organs. They agreed that for adult patients only blood group identical and compatible organs would continue to be offered, with identical blood groups taking priority. However, for children, identical and compatible patients registered on the urgent list would be prioritised above those with incompatible blood groups, regardless of time spent on the urgent list.

The Urgent Heart Scheme

Since the urgent heart schemes for adults and children were working well, Members agreed that the current payback arrangements would continue. The payback rule for adult donor hearts was inappropriate for Great Ormond Street, as the hospital does not have access to adult donors. Members would continue to monitor the effect of the scheme on individual units and review the scheme as appropriate.

Use of Donor Organs

Members were pleased to note that very few hearts from double lung donors had been lost to transplant as offers of unused hearts had been declined for a variety of appropriate reasons. Whilst there had been an increase in the number of multiple organ donors in the first half of 2000, there had been no corresponding increase in the number of cardiothoracic organ donors. This had resulted from a combination of factors: an increase in donor age and fewer donors from road traffic accidents. The effect of other factors such as demography, the distribution of neurosurgical critical care beds and local commitment to organ donation was also discussed. Members were pleased to hear that Ministers had considered organ procurement to be an important area and would be looking at ways to bring it within clinical governance.

Donor Age

Although very few donors over the age of 60 were suitable for cardiothoracic organ donation, Members agreed that the upper age limit for such donors should be increased to 65 years.

The Scottish Heart Transplant Service

Members were informed that since the previous meeting in March the Scottish and Newcastle heart transplant waiting lists had been merged, with arrangements for allocation of donor hearts based on clinical criteria. Newcastle had been contracted to carry out heart transplants for patients in Scotland until the end of March 2001: in the meantime a training programme had been established for the team working in Scotland. It was anticipated that transplant services would be re-established in Scotland when the Newcastle contract finished.

Consent for Research

Members recognised that there was a need to establish a framework to facilitate donor related research, such as the use of new preservation fluids which could impact on organ recipients from such donors.

National Specialist Commissioning Advisory Group

Meetings had been held with the cardiothoracic transplant units to agree the future configuration of cardiothoracic transplantation services in England. Two factors had influenced a recommendation from the National Specialist Commissioning Advisory Group that the number of units be reduced to four: the reduced number of donor organs available and the need to provide 24-hour cover through a one-in-four rota. Consensus would be sought on the future designation of transplant centres: it had been agreed that a single adult and paediatric unit would be established in London; one unit would be required to serve the Midlands; the units in Cambridge and Newcastle would operate within reconfigured zones.

ISORY GROUPS

LIVER ADVISORY GROUP

Members of the Liver Advisory Group met in Dublin on 7 November.

Donor Organ Use – Protocols and Guidelines

Initial statistical modelling had shown that, in general, liver patients with an estimated five-year survival greater than 50% were being registered for a transplant. To facilitate further modelling, the Directors of liver transplant units agreed to provide additional test results at registration. The ability to demonstrate equality of access to the waiting list was important and the development of a minimum clinical data set would need to be agreed with National Specialist Commissioning Advisory Group (NSCAG), in consultation with clinicians and UK Transplant.

UK Transplant had been working to introduce a data collection service to assist units for an initial period of 12 months. Resources for the collection of additional data would need to be considered by the Department of Health following submission of a business case from UK Transplant.

Liver Splitting

Although liver splitting had the potential to benefit an increased number of recipients, it was recognised that the impact on the liver transplant waiting list would be limited. This was due to the make up of the liver transplant waiting list in terms of suitably sized patients to receive either left or right lobes.

ABO Incompatibility

Members generally felt that it was inappropriate for patients to be transplanted with livers from incompatible blood groups and agreed that no changes should be made to the Donor Organ Sharing Scheme. Nevertheless, a paper to explore the potential use of ABO incompatible organs for routine liver grafts would be prepared for the next meeting.

Fast Track Offers

In cases where non-zonal livers are accepted for super urgent patients for whom the transplants do not proceed for recipient reasons, the organ will first be offered back to the zonal retrieval team. If not accepted by the zonal team the liver will be offered through the Fast Track Scheme. When more than one centre responds positively to the Fast Track offer of any liver from the UK or Republic of Ireland the organ will be allocated to the centre highest on the liver centre rota.

Group 2 Patients

For efficient monitoring of transplant outcomes, Members agreed that full follow-up data should be provided for all patients, including those from overseas countries.

Waiting Lists

In order to avoid discrepancies, routine checking of waiting list information was acknowledged to be crucial for both transplant unit personnel and UK Transplant.

Conditional Donations

Members reiterated the need to guard against the possibility of accepting organs for which consent to donation may have been attached.

Communication

The importance of passing all relevant donor information to recipient centres was discussed. Members were reminded of the requirement within the MSBT Guidelines for the surgeon performing a transplant to review the relevant donor form and, if necessary, contact the donor co-ordinator to obtain any further information and test results. The surgeon performing the transplant is ultimately responsible for deciding on the quality of the donated organ and its suitability for a particular patient.

To verify that risks have been assessed in each case, it was suggested that surgeons should share with their local transplant co-ordinators and with the Duty Office their reasons for accepting organs from marginal donors. Additionally, surgeons should ensure that patients are aware of any

particular risk of infection involved in their particular transplant procedure and that they give their consent to the operation: this must be clearly recorded in the patient's notes.

Exporting centres are responsible for ensuring that all information is reported on the organ specific forms that must accompany each donor organ: this assists informed decision making by transplanting surgeons.

Review of Liver Transplant Services

Following the review of cardiothoracic transplantation completed by NSCAG, the Department of Health had announced that a group had been set up to develop commissioning guidelines for renal transplant services. NSCAG would later undertake a review of the liver transplant services. Consideration would be given to the size of teams and facilities in individual transplant centres, minimum size of transplantation programmes, criteria for admission to waiting lists and quality of access to services. Members hoped that directors of liver transplant units, together with UK Transplant would be invited to take an active part in this review.

Staffing Retrieval Teams

Agreement had been reached to assign 15 additional national training places to transplant surgery. Five were allocated to urology for renal transplant training, five to general surgery primarily for renal transplant surgery and five to general surgery for liver/abdominal transplantation. Together with the requirement for a minimum of five surgeons in each centre, it was anticipated that this would provide the means for full staffing of retrieval teams.

Additional News

Dr Peter Doyle, of the Department of Health in London, has been elected as Chairman of the Expert Committee on Organisational Aspects of Co-operation in Organ Transplantation (SP-CTO) of the Council of Europe, for the next two years.

Laraine Joy
Head of Advisory Group Executive

Small Bowel Transplantation in Children - *an update*

SMALL BOWEL TRANSPLANTATION AND INTESTINAL FAILURE

Dr Sue Beath, Consultant Paediatric Hepatologist, Birmingham Children's Hospital and Mr Jean de Ville de Goyet, Consultant Paediatric Transplant Surgeon, Birmingham Children's Hospital

Background

Severe chronic intestinal failure is a life-threatening disease and affects between 2 and 3 individuals per million. Parenteral nutrition (PN) was developed in the 1960s and 70s to the point where it is possible to maintain children and adults in a reasonable nutritional condition for months and years [1]. During the 1980s increasingly patients were being managed in the home environment despite the difficulties of delivering this highly technical and expensive form of care [2]. With increasing numbers of individuals on home PN, especially children, it has become apparent that there are some unacceptable complications [3,4]. In the UK currently there are around 80 children on PN and 10 to 20 are referred each year to Birmingham Children's Hospital because of severe problems of establishing venous access and PN related liver disease [5].

An alternative treatment for chronic intestinal failure is intestinal transplantation. This has been attempted since the 1950s but was not consistently successful until the early 1990s when two groups in North America (in London, Ontario

and Pittsburgh) were able to achieve 1 year survival of 70% [6,7]. The new potent immunosuppressant drug Tacrolimus has been essential in allowing small bowel allografts to be tolerated, although there is a higher rate of infection and lymphoproliferative disease because of the necessary increased exposure to immunosuppression.

Intestinal transplantation is still in the development stage internationally, although larger Centres with experience of at least 10 transplants are now achieving 3 year survival of 65% [8]. However, this still means that the transplant option is generally reserved for patients with life-threatening complications such as TPN related liver disease or recurrent line sepsis [9].

Birmingham Children's Hospital Experience

We have assessed 82 children with intestinal failure since 1989. Of these a quarter were so ill at the time of referral that they died within days/weeks of liver failure. Another quarter were not yet experiencing life-threatening complications and were not considered in imminent need of a transplant. The remaining patients (41) fulfilled the criteria for intestinal transplantation as follows:

1. Committed to PN because of irreversible intestinal failure.
2. Experiencing a major complication i.e. cholestasis (plasma bilirubin greater than 100 micromol/L) and/or impending loss of venous access for feeding catheters.

Of the 41 patients, 7 declined transplantation of whom 6 later died; 34 patients were registered for intestinal transplantation of whom 17 received intestinal transplantation (combined with liver transplantation in 14); the remaining 15 died on the waiting list and 2 children are currently waiting.

A learning curve

Because of a shortage of size-matched organs for infants the rate of transplantation between 1994 and 1997 was only 1 per year with a resultant waiting list mortality of 66% (12 out of 18 children registered for intestinal transplantation died on the waiting list). By the time transplants were carried out, the recipients were in poor condition. Of the 4 children transplanted there is one survivor who is well and free of PN nearly 4 years after his small bowel transplant.

Donor criteria

In 1998 the donor criteria were changed to enable infants 15 kg or less to stand a chance of being offered organs before they died on the list. The new donor criteria depended on an experienced retrieval and transplant team including two consultant surgeons one of whom retrieved the organs and applied an innovative cut down technique to allow up to a 5:1 size mismatch between donor and recipient in 10 cases (Figure 1) [10]. Compatible but non-identical blood groups have been accepted and utilised without an adverse effect on postoperative recovery.

Current survival

Since 1998 we have carried out 13 transplants at a rate of 5 per year. There are 10 survivors; all of them are off PN and at home (70% current survival). The waiting list mortality has also improved to 3/18 (16%).

The major differences from liver transplantation

1. A child with intestinal failure and liver disease is inherently very unstable and vulnerable to overwhelming sepsis. These patients have usually survived a difficult neonatal period with multiple abdominal operations and do not tolerate waiting a long time for suitable donor organs. For this reason the UK Transplant Liver Advisory Group have generously agreed that intestinal transplant candidates who also require a liver allograft should be given priority over all other candidates except for those with fulminant liver failure.
2. The small bowel allograft does not tolerate preservation well and there

must be minimal delay between harvesting and re-implantation. This adds to the demands made on the transplant co-ordinators and transplant team.

3. The overall amount of immunosuppression required to achieve tolerance of the small bowel is roughly twice that which would be necessary for a liver transplant alone. This means that the postoperative recovery is longer, typically around 6 weeks and is complicated by episodes of rejection and infection in most cases [11].

Summary

Small bowel transplantation is feasible and a highly successful form of treating intestinal failure. Small-scale studies from Pittsburgh and from our own experience suggest that it improves quality of life dramatically within 6 months [12,13]. Although small bowel transplantation is currently as infrequent as segmental lung transplant (4-8 per year), it is crucial to ensure that

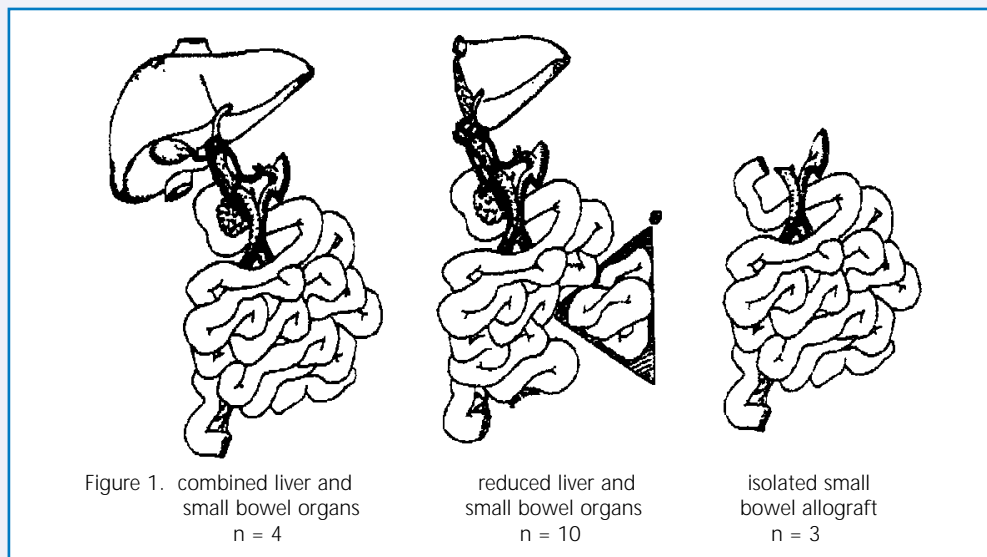
potential donor families are advised of the need for small bowel donation and of its dramatic impact on young children who would otherwise have died.

Acknowledgement

The information contained in this article should be regarded as preliminary; a manuscript is in preparation so that the results of the intestinal transplantation programme will be subject to peer review in the near future. We are indebted to the many nursing, medical and paramedical colleagues who have contributed to the development and success of the paediatric intestinal transplantation programme.

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References

1. Dorney SFA, Ament ME, Berquist et al. Improved survival in very short bowel of infancy with use of long-term parenteral nutrition. *J Pediatrics* 1985;107:521-5.
2. Puntis JWL. Home parenteral nutrition. *Arch Dis Child* 1995;72:186-90.
3. Dollery CM, Sullivan ID, Bauraind O et al. Pulmonary embolism and long term central venous access for parenteral nutrition. *Lancet* 1994; 344:1043-5.
4. Colomb V, Goulet O, De Potter S, Ricour C. Liver disease associated with long-term parenteral nutrition in children. *Transplantation Proc* 1994; 26:1467.
5. Beath SV. Demand for pediatric small bowel transplantation in the United Kingdom. *Transplantation Proc* 1998;30:2531-2.
6. Grant D, Wall W, Mimerault R. Successful small bowel-liver transplantation. *Lancet* 1990;335:181-4.
7. Todo S, Tsakis A, Abu-Elmagd K et al. Cadaveric small bowel and small bowel-liver transplantation in humans. *Transplantation* 1992;53:369-76.
8. Langnas AAN, Shaw BW, Antonson DL et al. Preliminary experience with intestinal transplantation in infants and children. *Pediatrics* 1996;98:443-8.
9. Goulet O, Jan D, Brousse N, Revillon Y, Ricour C. Intestinal transplantation. *J Pediatr Gastroenterol Nutr* 1997;25:1-11.
10. de Ville de Goyet J, Mitchell A, Mayer AD, Beath SV, McKiernan PJ, Kelly DA, Mirza D, Buckels JAC. En-bloc combined reduced-liver and small bowel transplants: from large donors to small children. *Transplantation* 2000;69:555.
11. Beath SV, Kelly DA, Booth IW et al. Post operative care of children under-going combined small bowel and liver transplantation. *Br J Int Care* 1994;4:302-8.
12. Sudan DL, Iverson A, Weseman RA, Kaufman S, Horslen S, Fox I, Shaw BW, Langnas AN. Assessment of function and quality of life long term after small bowel transplantation. *Transplant Proc* 2000 (in press).
13. Kosmach Park B, Reyes J. Quality of life (QOL) outcomes following pediatric small bowel transplantation. *Transplant Proc* 2000 (in press).

NETTING TRANSPLANT DATA - Roadshow Follow-up

For three weeks during October the intrepid UK Transplant Roadshow team toured the highways and byways of mainland Britain, on a mission to demonstrate to staff in the transplant services and the wider NHS the full range of data transmission and statistical services now available electronically. A series of nine half-day events held in regional locations included opportunities for 'hands-on practice' and feedback discussions.

The development and roll-out of the new external user applications is one of the most ambitious projects ever tackled by the Authority, involving a huge amount of effort in all work areas (see *Users' Bulletin* Issue No 37 Summer 2000). The Roadshow team were the ones 'out there', but we felt a real responsibility to represent this co-operative achievement to the very best of our ability.

We were nervous and excited as we set off on the first leg of our travels. Would we be equal to the challenge and do justice to the colleagues we

were leaving behind? The very positive reaction of our audience at the first Roadshow in Stirling was repeated at each of the other locations, and so what began as a daunting prospect turned out to be a most excellent adventure. Our thanks to all of you who attended a Roadshow and participated in the discussions. It was your enthusiastic involvement and encouragement which made the team's experience of the Roadshows so rewarding and ensured that the whole endeavour was worthwhile.

Our overall impression is that members of the transplant and related services appreciated the opportunity to meet with each other and senior UKT staff to focus on ways of improving data transmission and the provision of statistical information. We certainly enjoyed meeting you and receiving your comments and suggestions.

But the work of the Roadshow programme did not stop when we returned to base. Indeed the real benefit of the Roadshows will be seen in the follow-up. We have

made a start on considering all your feedback and this will form the basis for planning the next phase of development of the external user applications. We plan to publish a special Roadshow Bulletin to report on all the discussions and give specific responses to frequently asked questions. The special Bulletin will be sent to all those who registered for attendance at a Roadshow and to everyone who normally receives this Bulletin. Please bear with us - we hope to have the report ready for distribution early in the new year, but there is a lot of other work to catch up with after three weeks on the road!

In the meantime, the roll-out of the external user applications to authorised account holders is well under way. The new service is already available via NHSnet, subject to local connection. Internet access is still being finalised and will be available by the end of November.

If you wish to register for a user account, please write for further information and application forms to Caroline Parker, Secretary to David Shute, Director of Operations at UK Transplant. Please note that you will require authorisation from your unit director.

Those of you who attended a Roadshow and have not yet returned a completed feedback form can still do so to the following Freepost address:

Information Executive
UK Transplant
FREEPOST (SWB 1474)
Patchway
BRISTOL
BS34 8ZZ

Anyone who could not make it to a Roadshow can obtain a copy of the delegate's information pack from the Information Executive (Tel: 0117 975 7490).

Judy Watt
Information Services Manager
UK Transplant



The Roadshow team - raring to go. From left to right: Saifi Hashmi, Head of Computing and IT; Mark Belger, Head of the Statistical and Audit Services Division; David Shute, Director of Operations; Andy Maxwell, Data Executive Manager; Judy Watt, Information Services Manager, and Julie Kiln, Biostatistician

UK National Audits of Liver and Intrathoracic Transplantation

Dr Chris Rogers, Research and Development Support Unit, North Bristol NHS Trust

The Royal College of Surgeons of England carries out national audits of liver and intrathoracic transplantation. These audits are commissioned from the College by the National Specialist Commissioning Advisory Group (NSCAG). The liver audit started in March 1994 and the intrathoracic audit in April 1995 and the two audits have now documented about 4000 and 3000 transplants respectively.

The objectives of the audits are:

- to monitor survival of patients who have received liver and intrathoracic transplants;
- to estimate survival for each centre that carries out these types of transplant;
- to develop methods of case-mix adjustment for comparing the outcome of transplantation across centres.

Because the types of patients (diagnoses and severity of disease) may vary between centres, the last objective is very important. The audits also help surgeons to address important research questions about risk factors for failure of transplants, since the databases contain detailed information about the clinical characteristics of donors and recipients.

The audits function in a symbiotic relationship with UK Transplant. Many items of data are collected specifically for the audits (either using purpose-designed data collection forms or electronically). These data are entered into the main database at UK Transplant and the audit staff receive extracts from the main database, which includes both audit specific data, and data collected by UK Transplant for other purposes.

On receipt of the data, the audit staff initiate two different kinds of data

check. First, computer programs highlight all items of data that are missing or that appear 'suspicious', either because the data are outside the expected clinical range or because combinations of clinical characteristics do not 'add up'. Suspicious data are checked with centres and corrections made as appropriate. Feedback from this process, for example where suspicious data are confirmed as being correct, allows the computer programs to be updated, both by modifying the checks that are made and by suppressing subsequent queries of data that have been checked. Quality of data is indicated by >95% follow-up and few missing data (<5%) for key clinical data items.

A second check is made by validating all of the data in the database against patients' case notes and other hospital data sources for a random sample of patients in each centre. Data for a sample of patients in each centre are checked about once every nine months. This process allows the audits to quantify the overall quality of the data, which is very important when interpreting the findings from analyses.

As indicated by the objectives of the audits, there are two main types of output, contractual and academic. The first includes interim and annual reports to NSCAG, summarising the outcomes of participating centres and progress in developing case-mix models. The second includes conference presentations and peer-reviewed publications. Examples include the development of a risk model for predicting survival after heart transplantation^[1], outcomes with marginal heart donors^[2] an assessment of quality of life following lung transplantation^[3], an overview of patients presenting for liver transplantation during the five years 1994 to 1998^[4], and descriptive reviews of clinical practice and results for both intrathoracic^[5] and liver transplantation.

There are a number of projects planned for the near future. These

include extending the intrathoracic transplant database to include measures of quality of life, a further refinement and validation of the risk model for heart transplants, defining the primary indications for liver transplantation in the UK, an analysis of super-urgent liver transplantation, an assessment of hepatic re-transplantation and liver transplants performed for viral infection.

The audits increasingly serve as an important information resource to the transplant community and requests for data and analyses are welcomed. Further information is available from the research fellows, Imran Saeed – cardiothoracic audit and Sanjaya Wijeyekoon – liver audit (Tel: 020 7869 6620).

References

1. AC Anyanwu, CA Rogers and AJ Murday. An empirical model for risk stratification in adult heart transplantation - a multi-institutional study. *European Journal of Cardiothoracic Surgery*. 16, 4, 424-8 (1999)
2. AC Anyanwu, CA Rogers and AJ Murday. Should recipient risk be a factor in choosing recipients for sub-optimal donor hearts? *Transplantation Proceedings* 31, 1399-1400 (1999)
3. AC Anyanwu, A McGuire, CA Rogers and AJ Murday. Assessment of quality of life in lung transplantation using a simple generic tool. *Thorax* (in press)
4. P Hartley, A Petruckevitch, B Reeves and K Rolles. An overview of patients presenting for liver transplantation between 1994 and 1998. *British Journal of Surgery* (in press)
5. AC Anyanwu, CA Rogers and AJ Murday. Variations in cardiac transplantation - Comparisons between the United Kingdom and the United States. *Journal of Heart and Lung Transplantation* 18, 297-303 (1999)

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National Kidney Allocation Scheme

The current National Kidney Allocation Scheme was introduced on 1 July 1998. As agreed at implementation, the results of the first two years of the Scheme are being reviewed in detail. A full report is being prepared for the Renal Transplant Services meeting on 23 January 2001; a short overview of the key results was prepared for the November Kidney and Pancreas Advisory Group meeting. This summary of the overview report compares results of the first two years of the Scheme with the last 18 months of the previous Scheme.

($p < 0.0006$). In the two-year period, 25% of all retransplants were 000 mismatched compared with 16% previously.

Of the total 000 and favourably matched adult kidneys allocated through the National Scheme (1109; both local and exchanged), 70% required the use of recipient points scores as a tiebreaker to differentiate between patients.

In cases where the use of points as a tiebreaker was necessary, the mean points score for the patient receiving

bases under the current Scheme and thus comparisons with the previous Scheme are not possible. Changes with regard to the other four points scoring factors have been investigated and are summarised in Table 2.

Recipient age. When considering local and national kidney allocations to adult recipients, the mean age at transplant was significantly younger for adults transplanted between July 1998 and June 2000, compared with those transplanted in the period January 1997 – June 1998 ($p < 0.04$). In looking at local and national allocations separately, transplanted recipients were younger than previously for nationally allocated kidneys ($p < 0.01$) but not for locally allocated kidneys ($p = 0.7$). The mean age of adult recipients transplanted through the national Scheme since 1 July 1998 has remained at approximately 43 $\frac{1}{2}$ years whereas the corresponding mean for the 18 months prior to this was approximately 45 years.

Donor-recipient age difference. When considering all adult kidney transplants, donor-recipient age differences were significantly smaller for transplants carried out in the two years since the current Scheme was introduced compared with the previous 18 months ($p < 0.0001$). The differences were significant for both nationally and locally allocated kidneys ($p < 0.0008$ and $p < 0.02$, respectively), partly due to a

Table 1

HLA matching results					
	No. of transplants	% 000	% favourable	% non-favourable	% local
Adult transplants					
Jan 1997 - June 1998	1923	7	43	50	71
July 1998 - June 2000	2377	13	51	36	56
Paediatric transplants					
Jan 1997 - June 1998	152	5	31	64	17
July 1998 - June 2000	196	13	39	48	20

TRANSPLANTS

There has been a clear improvement in HLA matching during the first two years of the current National Kidney Allocation Scheme compared with the previous 18 months. Table 1 shows the proportion of 000, favourable and non-favourable adult and paediatric transplants for the first two years of the Scheme compared with the previous 18 months. There have been significant improvements for adult and paediatric transplants ($p < 0.0001$ and $p < 0.003$, respectively), achieved through greater exchange of organs between centres/alliances. Highly sensitised patients (HSPs) have also fared very well under the current Scheme: there has been a threefold increase in the number of 000 mismatched grafts for HSPs to 68 in the two years since 1 July 1998.

HLA matching results have improved significantly for both first transplants ($p < 0.0001$) and retransplants

the kidney was 27.9 (s.d. 5.5). This has remained relatively constant over the two years, as expected. The maximum possible points score is 48.5.

Sensitisation data and Balances of Exchange are calculated on different

Table 2

Summary data for points scoring factors for nationally allocated kidneys to adult recipients					
	Previous scheme		Current scheme		p
No. of transplants	580		1109		
Mean recipient age (s.d.)	45.3	(13.2)	43.7	(12.6)	<0.01
Mean donor-recipient age difference (s.d.)	15.5	(11.6)	13.4	(11.1)	<0.0008
Matchability points score	1-2	47%	40%		<0.03
	3-7	43%	49%		
	8-10	10%	11%		
Median waiting time (IQ range)	336	(135-669)	439	(173-910)	<0.0001

- A Review of the First Two Years

one-year increase in mean donor age over this period. However, the mean age difference has decreased by two years for national allocations, which would suggest that points scoring is having an additional effect.

Matchability. Generally a high proportion of adult patients with a matchability score of 1 (easy to match) are transplanted due to the nature of the three tier system. For local allocations there has been no significant change in the matchability distribution of the adult transplant recipients when comparing the periods January 1997 – June 1998 with July 1998 – June 2000. For national allocations, however, there is significant evidence that proportionally more transplants are carried out in patients with a matchability score between 3 and 7 at the expense of those who are easiest to HLA match ($p < 0.03$). This suggests that there has been a shift towards grafting those patients who are generally more difficult to HLA match, although there has been no change for the 30% of patients on the waiting list who are most difficult to HLA match.

Waiting time. The median waiting time of transplanted adults receiving nationally allocated kidneys has increased significantly from 336 days for the 18 months before the current Scheme to 439 days for transplants in the first two years of the Scheme ($p < 0.0001$). Waiting times for patients on the waiting list have also increased;

however, it is not clear whether longer waiting patients have benefited through points scoring.

Sensitisation. The rate of non-reporting of sensitisation data has decreased, and at the end of June 2000 7% of patients on the active waiting list had no sensitisation data recorded on the National Transplant Database.

Balance of Exchange. At 1 July 2000, centre Balances of Exchange ranged from -21 to +42 (-27 to +29 at 1 July 1998). The Balances were rolled over in February 2000 and kidneys are now counted if exchanged since 1 January 1998 (rather than 1 January 1997). No remedial action is planned because of the varying centre/alliance practices that contribute to the diverse range of Balances.

TRANSPLANT SURVIVAL

Sufficient data are available for univariate analysis of post-transplant outcome. Three-month follow-up returns for the latest grafts in the first two years of the Scheme have only just fallen due, but 70% of the grafts in the first 18 months have known outcome at three months.

In comparing this outcome with that of grafts carried out between 1 January 1997 and 30 June 1998 (for which three-month outcome is known for 92%), results in [Table 3](#) show that survival rates for first adult transplants have improved significantly. When looking at different HLA matchgrades,

three-month outcome for 000, favourable and non-favourable grafts have each improved and have reached statistical significance for 000 and favourably matched grafts ($p = 0.04$ and $p = 0.02$, respectively). Improved follow-up reporting and a multifactorial analysis are needed to provide more meaningful information.

SUMMARY

The effect of the current National Kidney Allocation Scheme has been positive in its first two years: HLA matching has improved significantly for adults and children and for both first graft and regrant recipients; there has been a threefold increase in the number of HSP 000 mismatched grafts; donor-recipient age differences have decreased; matchability points scoring may be having the desired effect of transplanting more patients who are difficult to HLA match. On a less positive note there is some evidence to suggest that adults receiving kidneys allocated through the national Scheme are younger than previously. This and other aspects of the Scheme will continue to be monitored.

Samantha Armstrong and Rachel Johnson
Statistical and Audit Services Division
UK Transplant

Table 3

Matchgrade	1 January 1997 - 30 June 1998			1 July 1998 - 31 December 1999			Log-Rank test
	No.	% survival	95% confidence interval	No.	% survival	95% confidence interval	
000	80	86	78-94	98	95	91-99	$p = 0.04$
Favourable	664	90	88-92	561	93	91-95	$p = 0.02$
Non-favourable	786	91	89-93	401	92	89-95	$p = 0.7$
All	1530	90	88-92	1060	93	91-95	$p = 0.01$

Three-month follow-up rates for the two periods are 94% and 73%, respectively

Factors affecting the Waiting Time to Kidney Transplant in the UK

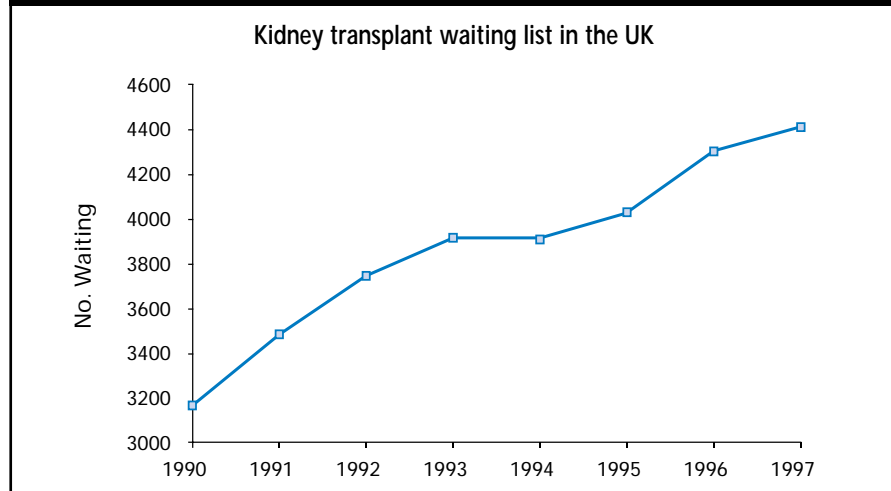
One of the sections of the forthcoming Renal Transplant Audit looks at factors found to influence the time a patient waits for a kidney transplant. The data used from the National Transplant Database covered all patients in the UK registered on the active national kidney waiting list between 1 January 1990 and 31 December 1997. 15916 adult registrations were analysed.

Waiting time was defined as the total time on the active waiting list. Periods of suspension were excluded as were recipients who were not registered prior to transplant. The outcome event is transplant, with patients dying on the list censored at date of death. Similarly, patients removed from the list were censored at date of removal and those patients still awaiting a transplant at 31 January 2000 were censored at that time. A Cox proportional hazards model was used to determine which factors influenced waiting time and Kaplan-Meier survival estimates were used to give median waiting times.

Of the 15916 adult registrations 64% received a transplant, 14% were still on the waiting list, while 22% were either removed or died on the waiting list.

The number of adult registrations each year have remained fairly constant over the eight-year period with just over 2000 new registrations each year. However, waiting times have increased over time, with adults waiting on average 14 months for transplant in the early 1990s compared with 19 months if registered in 1996 or 1997. This is due to the fall in donor numbers and is resulting in the growth of the waiting list (Figure 1).

Figure 1



The multifactorial model for adults found that year of registration, the patient's gender, age, diabetes, blood group, HLA homozygosity and the number of previous kidney transplants all had a significant effect on waiting time to transplant. Median waiting times for these factors are shown in Table 1.

Recipient gender was found to affect waiting times with females waiting on average three months longer for a transplant than male recipients. This is probably related to female recipients being more sensitised than males.

Waiting time was influenced by the age of the patient: waiting time increased with increasing age. Those patients aged over 60 at the time of registration waited five months longer than patients aged between 18 and 34.

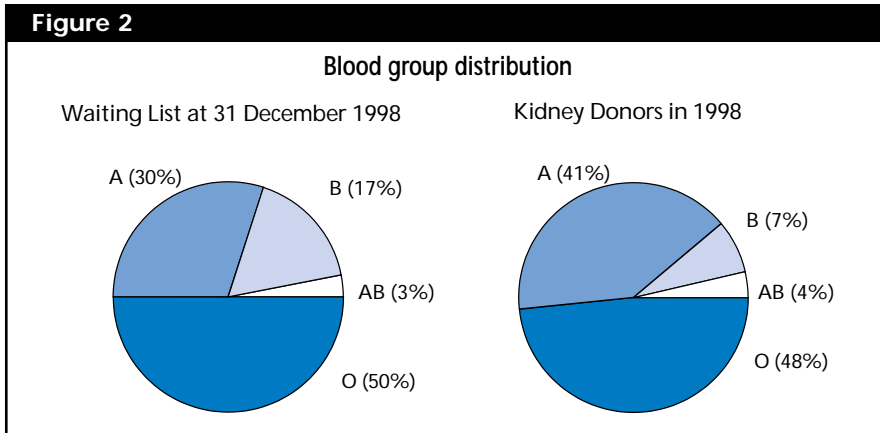
Diabetic patients waited two months longer than non-diabetic patients.

The patient's blood group significantly influenced the waiting time to transplant. Blood group B patients waited on average 31 months for a transplant compared with 22 months for blood group O patients and 10

Table 1

Median waiting times and 95% confidence intervals for time on the active national kidney transplant waiting list for registrations, 1 January 1990 - 31 December 1997				
Factor	Level	Median waiting time (days)	95% confidence interval	No.
Recipient registration period	1990-1992	416	394-436	6052
	1993-1995	496	471-527	6245
	1996-1997	583	547-631	4162
Recipient gender	Female	543	509-580	6141
	Male	451	431-468	9775
Recipient age (years)	18-34	438	407-462	3775
	35-49	473	442-497	5230
	50-59	493	464-535	3938
	60+	599	558-656	2973
Recipient diabetes	Non-diabetic	478	463-495	14595
	Diabetic	549	481-620	1321
Blood group	O	660	631-689	7308
	A	316	301-329	6062
	B	929	828-1040	1928
	AB	183	155-222	618
HLA-DR homozygosity	DR homozygous	1030	932-1146	2749
	DR heterozygous	426	411-441	13167
Number of previous grafts	None	430	416-447	13728
	One	1036	930-1172	1743
	> One	1802	1570-2426	445

Figure 2



months for blood group A, while blood group AB patients waited on average just 6 months.

The increased waiting times are due to the differences in blood group distribution between donors and patients awaiting a transplant. At the end of 1998, 17% of the national waiting list were blood group B, while only 7% of donors were blood group B

(Figure 2). Some local alliances have tried to give priority to blood group B patients, but this will generally be to the detriment of blood group O patients who wait significantly longer than blood group A and AB patients.

HLA-DR homozygous patients waited on average 20 months longer than HLA-DR heterozygous patients. This issue has been picked up by the UK

Transplant Kidney Advisory Group, and since 1 July this year preference has been given to HLA-DR homozygous patients when an HLA-DR homozygous kidney is available.

Finally, the analysis found that those patients with previous transplants waited longer than those waiting for a first graft. Patients with no previous kidney grafts waited an average of 14 months, while those with one previous graft waited 34 months and those with more than one previous kidney transplant waited 59 months.

An analysis of factors affecting time to retransplant is being undertaken. Initial results show that in addition to those factors found to affect first grafts, the number of HLA mismatches and the survival time of the first transplant also affect waiting time.

Mark Belger
Head of Statistical and Audit Services Division
UK Transplant

PATIENT REGISTRATION - *Check to be sure*

A core activity in the work of UK Transplant and one with direct impact on patient care is the accurate and timely registration of patients onto the National Transplant Waiting List. Of prime importance for renal patients, where the offer of an organ might be dependent on registration, it is also important for cardiothoracic and liver patients, since registration onto the national list provides an accurate national perspective of patients awaiting transplantation.

Within the Authority there is a clear understanding of the importance of this core activity and an undertaking that the National Transplant Database will be updated with each new patient registration (or amendment to existing patient records) on the day of receipt, or, where records are received outside of usual working hours, on the next working day.

Each month several hundred new registration records and a similar number of amendments are dealt with and stringent checks are in place to ensure accuracy and completeness of data capture. For example, with paper forms a double data entry system is used which requires that each form be input twice by independent operators and the input compared to highlight any input errors prior to the record being validated and committed to the National Transplant Database. In this way we have found that we can achieve very high levels of data input accuracy.

With the introduction of the new National Transplant Database the opportunity was taken to rewrite the applications used for processing data received from units

to include the facility to undertake detailed monitoring of individual records through the data capture process. At regular intervals throughout the day supervisory staff within the Data Executive monitor the progress of records being processed to ensure that all are committed to the database by the end of each day.

Any failure in the process is subject to immediate and rigorous investigation in order to find and tackle the root cause, and this provides an opportunity to continue to refine the process and put in place additional monitoring and checking procedures.

In addition to the work undertaken here at UK Transplant to ensure the quality of the data held, Units sending new registrations and amendments to patient records have a vital role to play in the quality process. Regular checking by Units of the waiting lists updated daily by UK Transplant and available to Units either electronically or on paper is the only way that Units can be completely sure that the data they have sent has been processed and is accurately stored in the National Transplant Database.

For this reason all Units are encouraged to undertake regular checks of the waiting list. Any unit which is unsure how to access an electronic version of their list or has a specific need for a paper version of the list should contact Julia Wilks in the Data Executive (telephone 0117 975 7519), who will be pleased to assist.

Andy Maxwell
Data Executive Manager
UK Transplant

Wolverhampton's Donor Campaign

- Lisa Potts lends a hand

Wolverhampton's Lisa Potts is lending her support to a town-wide campaign to boost the number of local people on the NHS Organ Donor Register.

The former nursery nurse who was awarded the George Medal for bravery, officially launched the campaign at the Wolverhampton Health Improvement development day on Friday, 6 October.

"Transplantation is one of the greatest success stories of our time. 3,000 organs and 2,000 sight-saving corneas are transplanted in the UK every year - enabling the majority of recipients to live a normal life", explained Lisa.

"However there is a constant need for suitable donated organs and corneas and this means that many other people - whose lives or sight could have been saved - are not able to get the vital help they need."

In the West Midlands alone 500 people are currently waiting for a kidney transplant and a further 100 are waiting for a heart, lung or liver. Yet out of a population of around 250,000 people, just 28,238 Wolverhampton residents have signed up to the NHS Organ Donor Register.

"The town is therefore launching a campaign - spearheaded by the Health Authority in conjunction with the Regional Transplant Educationalist - to boost the number of local people on the national register", she said.

The national register is a computerised record of a person's wish to donate organs for transplant. In the event of their death this information gives medical staff the confidence to approach the bereaved family knowing this is what the deceased wanted.

"If someone has already registered their wish to be a donor many families find it easier to support that wish rather than have to make the decision on their own. It is also a huge help if people pledging to donate organs tell their families what they wish."



Lisa Potts GM and Jordan Wiggan, aged six, kidney transplant patient

Beverley Cornforth, Regional Transplant Educationalist, added: "We are delighted Lisa Potts is lending her name to the Wolverhampton drive. This campaign will be the first time that a number of different organisations and agencies have joined together to raise awareness of the importance of organ donation - and the importance of registering the wish to donate and telling your family."

She added that there was no age limit for some donations and having an existing medical condition did not always prevent a person from becoming a donor. There was also a particular shortage of donor organs from the South Asian community in Britain because of the greater difficulty

of finding the right tissue match between donor and recipient.

People can register their details by completing an organ donation form available from many GP surgeries, chemists and dentists or by calling the Organ Donor Information Line on 0845 6060400.

Bev Cornforth
Regional Transplant Educationalist
(0121 421 7663. Mobile 0374 914500)

Transplant Team selected to represent UK at World Games

A squad of over 80 transplant athletes has been selected to represent Great Britain and Northern Ireland at The World Transplant Games in Kobe, Japan next year.

The transplant athletes have been chosen for their success at the ASDA Great North Millennium Transplant Games held on Tyneside this year. They are all gold or silver medallists and have proven their ability in their chosen sport.

Every member of the team has received a life-saving transplant and many would not be alive today without the generosity of their donor family.

The transplant athletes are wonderful to see in action as they are committed to succeeding in events that they would have not lived to see without their transplant. We have topped the medal table since the World Games first started in 1978 and I am confident that the team we have now selected will be able to do it again.

Each member of the team now needs to raise approximately £2,000 to cover their flight, accommodation, team kit and entry fees. If you would like to offer sponsorship to an individual athlete or make a donation to the team then please contact Bev Cornforth on 0121 421 7663.

Peter Griffin
British Transplant Team Manager
(0292 089 1541)



Standing left to right:

Terry MacKriel, Chairman, and Jane Eminson, Chief Executive, Wolverhampton Health Authority; Stuart Adcock, kidney transplant patient; Lisa Potts, George Medal holder; Maria Fanara, kidney transplant patient; Elizabeth Kirk, kidney transplant patient; Sue Moore, Renal Unit, New Cross Hospital; Michael Hayward, awaiting transplant and Chairman of New Cross Kidney Patients Association; Kay MacDonald, kidney transplant patient.

Kneeling left to right:

Susan Turner, Press and PR, Wolverhampton Health Authority; Tanya Adcock, first spina bifida kidney transplant patient (21 years ago) and Stuart's wife; Jordan Wiggan, aged six, kidney transplant patient; Bev Cornforth, Regional Transplant Educationalist

The ASDA Great North Millennium British Transplant Games

27 – 30 July 2000

Four years of preparation and planning were now over as transplant athletes from across the UK returned for the third time to enjoy the wonders of the Transplant Games in the North East.

We launched into the event with the now traditional Opening Ceremony held at Newcastle Civic Centre. Here the Lord Mayor and Lady Mayoress received the Olympic-style torch, which had travelled up from Birmingham, the hosts of last year's Games, and handed it over to Newcastle transplant athletes. Leann McKee, the first living related lung recipient ever to take part in the Games' 23-year history, read an Oath for all competitors.

Over 650 athletes of all ages took part in the core events of track and field athletics, swimming, racquet sports of tennis, badminton, table tennis and squash. Additionally, there was volleyball, bowls, golf and cycling, whilst for those interested in less strenuous competition there was snooker, darts and ten-pin bowling. Sailing and canoeing competitions were held as were three new events for this year, archery, fishing and driving skills.

The most transplant children ever to take part, 206, enjoyed a very busy weekend, which was a mixture of sport, fun events and outings to theme parks, such as Beamish Museum and Washington Wildfowl Park. Their events included badminton, table tennis, swimming, athletics, an obstacle race and the ball throw.

There were many truly memorable moments throughout the Games weekend, including Rowena Tomas-Breese, a blind transplantee, swimming her leg of the 4 x 50m freestyle relay and Horace Hibbet, running second in his race when he stopped, short of the finishing line, to pick up his opponent who had tripped and fallen. These memories are what make the Transplant Games so special.

One of the key reasons for hosting the Transplant Games in any city is to raise public awareness of the need for organ

donation and transplantation. We have, this year, generated more publicity than any previous Games. Before the start of the Transplant Games we had transplant athletes generating national coverage, for example on GMTV and in several features run by the *Daily Mail* as well as countless regional stories. During the Games a number of TV crews attended a variety of events; the weather forecast was broadcast live from the Opening Ceremony and a production company has compiled a half hour documentary purely on the Games. We had photographers and journalists at most venues, predominantly from the North East, but also many with a national interest, such as the *Nursing Times*. All in all we generated a wealth of coverage showing the benefits of transplantation that simply would not have happened without an event of this nature.

We are very grateful to our patrons – the North East athletics superstars, Brendan Foster, Steve Cram and Jonathan Edwards. They gave their time and support generously – we could not have had better patrons.

We are also grateful to all of our sponsors who, as always, help to make the event such a success. This year we are especially grateful to ASDA for their contribution as title sponsors, Nissan UK and the major transplant related pharmaceutical companies. Without the support of our sponsors the Transplant Games would be very difficult and expensive to run.

Organising the Transplant Games is hard work and involves lots of preparation but is such great fun and creates a wonderful team spirit within the Local Organising Committee. I am particularly grateful to all members of the LOC for making The ASDA Great North Millennium Transplant Games such a success.

R M R Taylor
Chairman Local Organising
Committee and the Transplant
Sports Association of Great Britain

BLOODLESS SURGERY IN LEEDS

Bloodless surgery, as it has been called, was pioneered in the US as a way of treating Jehovah's Witnesses, whose religion forbids the exchange of blood from one individual to another. Bloodless surgery is about minimising blood loss during surgical operations, recycling losses and using autologous transfusion.

Jehovah's Witnesses, who number approximately 145,000 in Britain, believe that the Bible forbids the consumption of blood. God told Moses "and you must not eat any blood in any places where you dwell, whether that of fowl or that of beast. Any soul who eats any blood, that soul must be cut off from his people" (Lev.7:26-27).

The Royal College of Surgeons and the Association of Anaesthetists believe that a patient's wishes should be respected. Any Jehovah's Witness who has a blood transfusion is deemed to have revoked their religion.

St James's Hospital in Leeds is one Trust in Britain which is able to offer bloodless surgery to devout Jehovah's Witnesses. The surgical transplant team in Leeds has now performed several successful bloodless renal and liver transplants. Their successes can be attributed to the meticulous skills of the surgeons, the development of new technologies and patient selection. Such surgery bestows the opportunity for individuals to exercise their privilege of choice.

Julie Jeffery
Transplant Co-ordinator
St James's University
Hospital, Leeds

Just another Day!

- an interview with a UKTFT Driver

Serving firefighter Tom Conway was chatting to a work colleague who is a voluntary driver for UK Transport for Transplants (UKTFT) in his spare time. Tom was very interested in this, felt he had some time to spare and decided to give it a go. That was about 12 months ago and he has thoroughly enjoyed every minute since.

Tom is just one of a team of drivers who are either serving or early retired emergency services personnel and have extensive experience of driving under 'blue light' conditions. When joining UKTFT they then undergo awareness training to give an understanding of exactly what the job entails.

The drivers work on a standby rota and Tom has said that usually when he receives a call he has just one hour to get ready, find out what hospital he has to report to and then pick up the vehicle from either Henrietta Street Ambulance Station in Birmingham or Burton Road Ambulance Station in Dudley. As Tom lives in Sutton Coldfield, just getting to either one of these stations and then on to the designated hospital can be a feat in itself, given that he only has one hour and is at the mercy of traffic conditions.

Although drivers are 'blue light' trained, emergency sirens are only used at the request of the co-ordinator travelling with them, for instance when transporting a heart. Staff at the Queen Elizabeth Hospital (Birmingham) help the process by ensuring that organs are stored in ice and in appropriate transport boxes so that Tom can quickly load the vehicle and be on his way. Tom's job is not just about transporting organs; he may also be responsible for carrying a medical team of up to five people; taking them to the donor hospital, waiting while they retrieve the organ, and then driving back to the transplant unit, where the patient is waiting for the operation to receive the donor organ.

Asked what problems the drivers encountered, Tom said that the main difficulty is traffic. He said that the co-ordinators are excellent in assisting the drivers in their job, ensuring that as much time as possible is given to the driver to enable the task to be carried out within the time constraints of the donated organs. It has been known for

vehicles to be blocked in when waiting at the hospitals, but steps have been taken to alert hospital staff to the fact that they are UKTFT vehicles to avoid such occurrences.

Besides heavy traffic, weather can have an adverse effect. When motorways are blocked, time can be lost trying to find another route to take. Tom recalled an occasion, in an older hospital, when the donor was on the top floor of the building and all the lifts had broken down! There was a considerable delay because the donor could not be moved to the theatre on the ground floor until the engineer had repaired the lifts. However, Tom still managed to deliver the organ well within the time limit.

Tom said: "I thoroughly enjoy working for UKTFT, although sometimes it can be frustrating when I am on standby - waiting for a call to come through. After a successful mission I get a great sense of satisfaction knowing that I have helped the medical teams in hopefully ensuring a better quality of life for someone."

He added: "We have a very good working relationship with both the co-ordinators and the medical teams. It can be interesting listening to them discussing how operations have gone."

The UKTFT drivers provide a very necessary, professional service, under sensitive conditions. They endeavour to do everything in their power to ensure that the medical teams and organs are delivered promptly. The UKTFT team always aims to provide an excellent service but is constantly looking to improve response/delivery times. Naturally they would welcome any ideas/suggestions for improvements to the standard of service from co-ordinators, medical teams, or from anyone who is involved in the transportation of organs.

If you have any ideas or suggestions to offer and would like to discuss them further please contact Corinne Young at UKTFT on 01384 215668.

Chris Capewell
Press Liaison Officer
West Midlands Ambulance
NHS Trust

INFORMATION FROM THE NATIONAL TRANSPLANT DATABASE

UK Transplant was recently pleased to be able to assist with a request for information about small bowel transplants in the UK. The National Transplant Database is the repository of a vast amount of data, dating back to 1972, and is a valuable source of donor, waiting list and transplant information.

Whilst we try to make information widely available, we are always receptive to suggestions for new areas of analysis or study. Indeed, part of the reason for setting up the Roadshows described on page 8 was to provide transplant and related services interests with an opportunity to specify the type of information to which they would like access on a regular basis. However, the new external user applications will not answer everyone's information needs. If you require centre-specific or other data which is not provided by these applications, then the statistical information team in the Information Executive will be happy to help. They can be contacted on 0117 975 7544.

If you have any suggestions about a specific study that you would like to see featured in this Bulletin please write to Judy Watt, Information Services Manager, with an outline of the information required.

Mark Belger
Head of Statistical and Audit
Services Division
UK Transplant

THE FOURTH TRANSPLANT West Midlands Region

TalkShop

continued from page 3

initiatives which we can use, and not stick with one."

Antony Hooker made the following proposal:

"What we want to suggest to the West Midlands is that what we need to do is have required referral. We need required referral of all impending and actual neurological deaths within the region, to the transplant co-ordinators....We have a generic hospital policy...but what we desperately need from each Trust is a clear mandate that supports organ donation...we have to have a clear pathway for the identification and the referrals of all donors – multi organ and tissue donors."

Jane Eminson spoke frankly about the role of commissioners and neatly summed up the lessons that were

learnt on the day:

"The solution has to come from everybody here, from the mixture of clinicians, the various staff, the public health people, the commissioners. It's only by that group of people talking, putting the proposals together, putting them into the system, will we get progress...it is a collaborative responsibility and presumably there will be a collaborative solution."

KATE WYATT
UK Transplant

A further article detailing the progress following this TalkShop, and the development of a partnership between commissioners and providers and members of the West Midlands transplant community, with the united aim of increasing organ donation, will be included in the next issue of the Bulletin.

Professor Sir Magdi Yacoub wins BBC 'People's Award'

On Sunday 8 October 2000, amid a crowd of celebrities, sportsmen and women, and members of the public, Professor Sir Magdi Yacoub was awarded the final and most-prized 'People's Award' for special achievement to people throughout his lifetime as voted by BBC viewers.

Professor Yacoub beat off fierce competition, including Sir Paul McCartney, Sir Richard Branson and Colin Parry. The award ceremony was hosted by Michael Buerk and Gaby Roslin, but the actual award was presented by two of Professor Yacoub's transplant patients; one was his longest surviving recipient and the other was a young girl who has now received two heart transplants.

Professor Yacoub was very gracious in his acceptance of the award, simply commenting that 'It is a great honour to receive this award, as I work with people, for people, and it was awarded by people'.

MY TRANSPLANT EXPERIENCE

I don't remember my Heart Transplant that well, but there is one memory that sticks in my mind. It was my third birthday and I got a hush-a-bye baby doll and a cradle for her to sleep in. I have a vivid memory that everyone was standing around me looking worried, it was as if they would lose me soon and I would never see them again.

I was really ill when I was little, you could say I was at death's door. I have seen photos of me when I was three, just an hour before my transplant. It sometimes upsets me to see my mum with tears in her eyes. Me looking small and white like a ghost. After my transplant I was fine and I was just a normal child living a normal life, but five years ago I had a really bad chest infection and ended up in hospital for just about eight weeks and when I

came out they had put me on tube feeding. The tube was in my nose. I had to go to school with it in, everyone used to balk at me when I went past them. I used to come home and cry into my Teddy Bears. I got a lot of support from my friends and family and also the nurse Penny who came to change the tube every week. I am still on tube feeding but the tube is now in my stomach, so it isn't as visible. I can't wear belly tops, but that doesn't worry me too much. If I really wanted to, I suppose I could decorate it and pretend it was a belly button ring! I am fine now and I am quite proud of my transplant. I have told everyone at school and none of them seem to care, they just treat me like they would treat anyone else.

Sometimes I do get frustrated because I am not allowed to sunbathe and if my mum sees one ray of sunlight, out

comes the factor 65 suntan lotion. Because I am on cyclosporin I have more chance of getting skin cancer, although I suppose when I am a bit older I can just stick a bit of fake suntan on. Now I try to enjoy every minute of my life, and I appreciate every detail of it. This year it is my tenth anniversary of my Heart Transplant. I plan to celebrate by going to a teddy bear Museum and then going to a restaurant and stuffing my face full of spare ribs with barbecue sauce and then just to top it up nicely a chocolate fudge cake. I love my life and I wish to have it till I am ninety.

Emma Thompson (aged 12)
North Yorkshire
(Overall winner of Millennium Transplant Games Children's Competition)

Puzzle Page

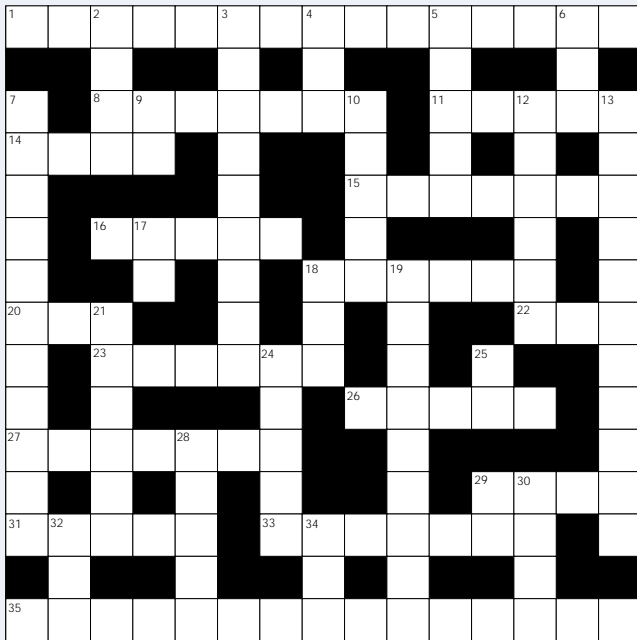
Last November dedicated staff at UKTSSA compiled puzzles to help transplant colleagues cope with the Millennium. A lot has happened since then, but puzzling is still a core activity of UK Transplant.

Solutions to these puzzles will be given in the Spring 2001 Bulletin. No magnificent prizes are on offer, but we promise to publish your name if you send in a correct solution (in an envelope marked Puzzle) to the Information Executive.

Are there enough puzzle fans out there to help us make this page a regular feature?

Send in your puzzles - be as creative and cryptic as you like - and you will make some UKT staff very happy.

The Cryptic Crossword



Crossword Clues

Across

1. Model organised a scheme in Waterloo, for example, for our subject. (15)
8. Marshall surrounded by children as one of the 23 ac for 1 ac. (7)
11. Cause an obstruction in the heart and lungs. (5)
14. Laos is in a state too. (4)
15. Curb pus carefully as surgeons do before an operation. (5-2)
16. See 31.
18. Flexible one in firm establishment. (6)
20. The boat describes a curve. (3)
22. Students come back for the Daily Star (or another paper). (3)
23. Pipe, maybe, the subjects of 1. (6)
26. Car crash on the bypass. (5)
27. Singe it badly and it catches fire. (7)
29. Man, perhaps, lies about. (4)
- 31 & 16. Mixed lamb well so ended up with innards (for 1?). (5,5)
33. Inactive, wipe your feet on it having lost a ring, name inscribed. (7)
35. I lie swimming in compost bath and so have agreeable tissues. (15)

Down

2. Bird flies up to others with a call like 6's. (4)
3. With cooking vessel, make the last point become a number of 23. (9)
4. A lot lose their head - whatever. (3)
5. Sound trees used as a rotating shaft. (5)
6. Bird, losing tail, flies up to another, sounds like one of 2. (3)
7. Get a funny idea, scrap it for children. (11)
9. Yours truly in debt, it is said, for the moon. (2)
10. Sails tied up with string. (5)
12. Alternative pieces, possibly remove to facilitate 1 of 21. (6)
13. Hardy involvement of a strategy and setter for a technique for survival. (6-5)
17. See 25.
18. Drink up - horrible yellow greenish fluid! (3)
19. I am and each is involved in a bloodless time. (9)
21. Eye membrane (in 1) is a seed container, by the sound of it. (6)
24. Plummet head first - I've gone and investigated surreptitiously. (5)
- 25 & 17. A French refusal is unknown. (4)
28. Mancunian 21 1 specialist is out, returning about the last half of the fall. (5)
29. If a player 30 up they are this. (2)
30. Crazy over puncture. (4)
32. 9 comes up to Frenchman and me. (3)
34. There will be some resistance if you ring the queen. (3)

Transplanted Wordsearch

N	O	I	E	C	I	F	F	O	Y	T	U	D	S	C	H
S	A	E	R	C	N	A	P	Q	U	K	I	T	H	O	T
H	T	T	R	A	P	L	A	N	T	I	G	E	N	S	A
A	L	R	N	D	U	V	E	R	R	D	O	N	C	I	E
N	K	J	A	E	I	C	A	D	A	V	E	R	I	C	D
T	G	I	L	N	I	N	O	P	K	I	T	E	L	I	M
G	R	T	L	F	S	P	A	R	E	L	C	S	O	I	E
N	A	R	E	P	I	P	I	E	N	O	Y	C	T	Y	T
I	F	N	L	B	R	A	L	C	O	E	L	U	S	E	S
H	T	A	E	R	D	P	I	A	E	P	A	H	Y	N	N
C	N	S	B	O	H	S	V	D	N	R	Y	E	S	D	I
T	I	H	M	N	W	H	E	A	S	T	H	A	A	I	A
A	L	I	T	O	S	U	R	I	L	F	A	R	E	K	R
M	N	M	E	D	G	L	A	V	E	I	R	T	E	R	B
O	A	L	N	K	N	A	L	L	O	C	A	T	I	O	N
D	C	H	G	R	U	R	E	C	H	L	R	O	Y	O	R
L	E	W	O	B	L	L	A	M	S	E	B	D	O	E	N

Wordsearch Clues

- | | | |
|------------------|-----------|-------------|
| ITU | ASYSTOLIC | DUTY OFFICE |
| UK TRANSPLANT | DONOR | CORNEA |
| HEART | CADAVERIC | ALLELE |
| RECIPIENT | NHS | ALLOCATION |
| LIVER | RETRIEVAL | GRAFT |
| LUNGS | ANTIGENS | SMALL BOWEL |
| TRANSPLANTATION | HLA | ODR |
| PANCREAS | MATCHING | HSP |
| BRAIN STEM DEATH | SCLERA | |
| KIDNEY | DOMINO | |

Transplant Statistics

1 January 2000 to
30 September 2000

Active = Active patients
Sus = Patients temporarily suspended

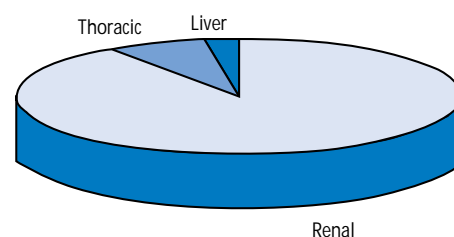
These statistics are provisional and subject to some modification (mainly due to belated notifications). Comparisons are given with activity during the same period (January to September) in 1999. Percentage changes are given when the activity rate is at least 10.

The number of donors reported in 2000 was 618 compared with 607 in 1999.

National Transplant Waiting List at 30 September 2000

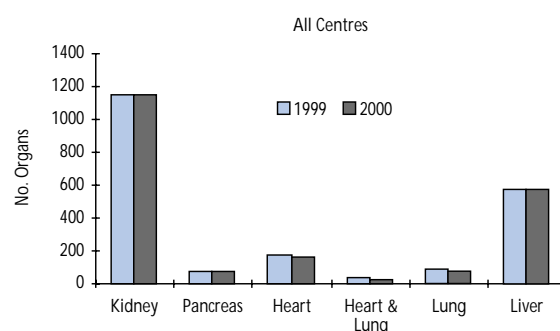
Organ	UK			Republic of Ireland			All Centres Total
	Active	Sus	Total	Active	Sus	Total	
Kidney	4805	1153	5958	0	158	158 *	6116
Kidney & Pancreas	64	21	85	0	13	13 *	98
Pancreas	15	8	23	0	1	1 *	24
Heart	168	10	178	23	0	23	201
Heart & Lung	101	4	105	2	0	2	107
Lung	203	5	208	0	0	0	208
Liver	137	6	143	23	0	23	166
Total Waiting	5493	1207	6700	48	172	220	6920

* Republic of Ireland operates its own Kidney allocation scheme



Cadaveric solid organ donors reported to UK Transplant, classified by organs donated

Organ	UK			Republic of Ireland		
	1999	2000	%change	1999	2000	%change
Kidney	1042	1057	1	103	88	-15
Pancreas	67	72	7	3	7	-
Heart	155	139	-10	17	18	6
Heart & Lung	37	25	-32	3	0	-
Lung	86	70	-19	4	8	-
Liver	521	524	1	52	45	-13
Total Organs	1908	1887	-1	181	166	-8
Total Donors	552	571	3	55	47	-15



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

Organ	UK			Republic of Ireland			Total		
	1999	2000	%change	1999	2000	%change	1999	2000	%change
Cadaveric Kidney	984	966	-2	93	81	-13	1077	1047	-3
Live Kidney	199	231	16	2	0	-	201	231	15
Kidney & Pancreas	27	25	-7	3	6	-	30	31	3
Pancreas	4	1	-	0	1	-	4	2	-
Cadaveric Heart	160	145	-9	4	9	-	164	154	-6
Domino Heart	17	10	-41	0	0	-	17	10	-41
Heart & Lung	38	24	-37	0	0	-	38	24	-37
Lung	78	68	-13	0	0	-	78	68	-13
Live Lung	4	0	-	0	0	-	4	0	-
Liver / Liver Lobe	510	482	-5	19	31	63	529	513	-3
Live Liver / Liver Lobe	11	6	-	0	0	-	11	6	-
Total Solid Organ Tx	2032	1958	-2	121	128	6	2153	2086	-3

Conference diary

2001

Renal Transplant Directors' Meeting
Tuesday 23 January, Royal College of Physicians, London

Information: Laraine Joy, Advisory Group Executive, UK Transplant Invitations will be extended to Directors of Renal Transplant Units, Heads of Tissue Typing Laboratories and an additional nominee from each transplant centre.

1st British Symposium on Organ Preservation

23 February, The Royal Society of Medicine, 1 Wimpole Street, London W1

Information: Mrs H Tindall, PA to Nadey S Hakim, St Mary's Hospital, Praed Street, London W2 1NY

Tel: 020 7886 1217
Fax: 020 7886 1707

Non Heart Beating Donation - a one day symposium

7 March 2001, Postgraduate Medical Education Centre, Freeman Hospital, Newcastle upon Tyne

Information: Carol Mayes, Room 122F, Level 1, Freeman Hospital, Newcastle upon Tyne, NE7 7DN

Tel: 0191 223 1218
Fax: 0191 223 1219

E-mail: pam.buckley@nuth.northy.nhs.uk

RCN Nephrology Nurses Forum - Annual Conference - Creativity in Clinical Practice

10 March, Royal Institute of British Architects, London

Information: Kay Mirza, Conference Department, Royal College of Nursing

Tel: 020 7647 3581
Fax: 020 7647 3412

E-mail: kay.mirza@rcn.org.uk

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

13th Annual Conference of the Australasian Transplant Co-ordinators Association

1-4 April, Rydges Hotel, Canberra, Australia

Information: Contact Ralph Maddison
E-mail: donornz@ahsl.co.nz

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.ppscmc.org/ici

NOTICES

Caldicott Reminder SAFE HAVEN FOR FAXES

In order to comply with Caldicott guidelines for safeguarding patient-identifiable information, UK Transplant has established the following safe haven procedure for faxed information:

- Any patient-specific information which must be faxed to the Authority should be sent only to the safe haven fax machines in the Duty Office (Fax: 0117 975 7599) or in Data Executive (Fax: 0117 975 7570).
- Any other confidential information which must be faxed to the Authority should be sent to the Chief Executive's Office (Fax: 0117 975 7502).

All transplant units and tissue typing labs are reminded that the faxed transmission of patient-specific information should be kept to the minimum required for direct patient care.

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

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