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UKTSSA
United Kingdom
Transplant Support
Service Authority

USERS' BULLETIN

for the transplant community

ISSUE NO 36 SUMMER 2000

IMPROVED DONATION RATES - A REASON FOR HOPE?

Organ donation rates in the first three months of 2000 have shown a significant improvement over the same period last year: cadaveric kidney and liver donation in the UK increased by 16% and 13%, respectively, with a corresponding increase in the numbers of transplants. There has also been a 70% increase in living kidney donation which points to targeted efforts by many units to lessen the gap between supply and demand.

After last year, which showed particularly bad donation rates, every sign of improvement is welcome. What is more encouraging, however, is that the same trend has been recently reported in the countries represented by Eurotransplant. It is too early to do more than speculate about the reasons behind these developments, but we shall continue to monitor the trends and report them as fully as possible. See page 15 for detailed quarterly statistics.

www.uktransplant.org.uk

The Authority website was launched in May by John Shaw, Chairman of the Special Health Authority:

"With almost 6,000 people currently waiting and hoping for a transplant, the facts about transplantation - its successes and its limitations - are being sought by ever increasing numbers of people.

The new UKTSSA website is about making these facts, drawn from the National Transplant Database which we maintain, more easily available to a wider audience.

As a result, we hope to encourage a better understanding of how transplantation works in the UK and the vital importance of organ donation to its success.

Transplants are a great success story within the modern NHS. The challenge now is to make this news spread more widely and encourage more people to be part of that success by discussing the issues and agreeing to register as potential donors. They will find all the information they need, including how to register on the NHS Organ Donor Register, on this website, which will be up-dated every day."

Trevor Jones, UKTSSA Webmaster, helps Chairman John Shaw to make the first public access to our website

The UKTSSA website is a significant step in the Authority's strategy to build on the National Transplant Database investment. This Bulletin describes the intranet and internet access which is now available not only to transplant service users, but also to the wider NHS, Government Departments and the public at large. (See page 3 of this Bulletin.)

The website provides a range of information - see page 2.

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

THE SPECIAL HEALTH AUTHORITY

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The website provides a range of information:

About Transplantation which gives answers to the most frequently asked questions, information on kidney transplants in children, and much more.

For those who need statistical information, there is access to the many publications we regularly produce with the help of our Advisory Group colleagues.

About UKTSSA includes the background and history to the Special Health Authority, details of the Users' Advisory Groups, organ matching and allocation protocols, and the Authority's Annual Report. Employment opportunities at UKTSSA will also be posted here.

The section on the **Donor Card** provides some background information on the NHS Organ Donor Register and will link to the Department of Health's organ donation website (currently being developed) which will facilitate online registration.

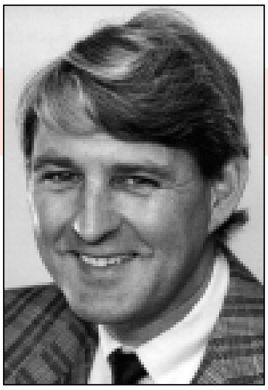
The **Home Page** will be updated each day with the cumulative numbers of transplants and organ donors in the year, and the current number of patients awaiting a transplant. It will also provide an information update on any topical donation and transplant issues and any relevant news stories.

There will also be **Useful Links** to other sites (both at home and abroad) which provide information about transplantation and/or support for transplant patients.

This is only the start. The site will be developed over time to reflect changes and developments in the world of transplantation and the interests of different users. We hope that patients, the professionals involved in donation, transplantation and related services, and the public at large will come to view the site as a reliable source of factual information. We also hope that it will help to raise awareness of the issues surrounding transplantation and the need to increase the number of donors.

Please access the site and let us know what you think. Let us have any suggestions or comments. We may not be able to meet everyone's wishes - or do so immediately - but we will listen and will do our best to respond to ideas and suggestions received. Contact Trevor via infoexec@uktssa-info.demon.co.uk. A direct hit via the website will be possible from July onwards.

A TRIBUTE TO TERRY RAY ON HIS RETIREMENT



Terry Ray, Head of Laboratory Services at UKTSSA, started his career in 1959 as a Student Technician in the South West Regional Blood Transfusion Service. Guided by Dr John Lockyer and Ernie "Mac" Day he qualified for Fellowship of the Institute of Biomedical Sciences in the first year of the new advanced level examination. After heading up the South West Regional Production Blood Grouping Reagents Section Terry moved into automated Blood Grouping.

In 1973 Terry transferred to Tissue Typing, continuing the reagents theme with the "National Plate" of HLA A&B reagents. Together with Colin Entwistle and Godfrey Laundy he took on the collation and international distribution of all the serological reagents for the 7th International Histocompatibility Workshop held in Oxford in 1977. Exciting times were ahead, starting with the merger of the National Tissue Typing and Reference Laboratory (NTTRL) and the National Organ Matching and Distribution Service (NOMDS) to become UK Transplant Service in 1979, under the Directorship of Ben Bradley. The next highlight was the development in 1980 of the first National DR typing tray in collaboration with Julia Bodmer and the UK Tissue Typing Research Group, introducing HLA Class II typing into transplantation laboratories.

The Quality Control (QC) function had always been close to the heart of the NTTRL, and annual exercises were developed to compare crossmatching sensitivity and complement activity as well as typing accuracy. The UK QC exercises eventually metamorphosed into the National External Quality Assessment Scheme (NEQAS) for H and I under Peter Klouda's guidance. The demise of serology was heralded by the RFLP analysis for HLA Class II which Jeff and Liz Bidwell took forward and the 1D gel Biochemistry which Peter Klouda and Martin Guttridge developed for investigating HLA Class I typing problems.

Improvements in patient services came with the Beneficial Matching Scheme of Gilks, Bradley and Gore and the exchange of sensitised patients' sera through the national SOS scheme to find crossmatch negative kidneys for the most difficult patients. In the background, numerous projects and studies were taking place: the European Dialysis Transplant Association Registry, the National HLA Study, the IMUST, the Monoclonal Typing Reagents Programme, the Bank of EBV transformed Cell Lines, the BTS Bone Marrow Donor Registry, the British Bone Marrow and Platelet Donor Panel, and various Histocompatibility Workshops.

The UK Transplant Service transformed into UKTSSA in 1991 when the focus was on the absolute need to supply central services which would be valued and which Users could not sensibly provide locally. Terry joined the Special Health Authority Board in 1994 and with Professor Richard Batchelor and Sir Peter Morris enthusiastically supported the PCR-SSP and flow cytometry training courses from 1994 to 1996. The decision to back the establishment of a national HLA sequencing facility under Joe Ross, to provide a service which could not be economically provided locally, was another example of this focused and forward-looking approach.

More than anyone else at UKTSSA, Terry has seen transplantation emerge, develop, grow and mature. He can take particular pride in having been part of the team which set the gold standard against which tissue typing is judged not only UK-wide but, increasingly, world-wide. The science and technology which was developed largely in Bristol and which formed the NNTRL and its National Serum Bank have now, in effect, done their job. Tissue typing is standardised and most local laboratories are now able to match - in many instances - the standards which Terry has been instrumental in maintaining in Bristol.

Terry is understandably sad to see the end of laboratory services at UKTSSA, but he can be justifiably proud of masterminding a plan to secure the future of his staff and give them an excellent chance of developing valuable services in new locations.

All Terry's colleagues at UKTSSA and its predecessor organisations, and the Members of the Special Health Authority, are enormously appreciative of his commitment to public service over so many years. There are well over 24,000 people in the UK who owe their successful transplant to the pioneering work undertaken in Bristol in the 1970s. Some achievement!

We send him our very best wishes for an enjoyable retirement. Terry may be leaving UKTSSA, but the legacy of his commitment will live on.

Increased Corneas for Corneal Transplant Service : Norfolk & Norwich*

Pioneering teamwork at the Norfolk and Norwich Hospital has led to a huge increase in the number of corneas being sent to the Corneal Transplant Service (CTS) eye bank for transplantation.

Now it is hoped that other hospitals will follow the example being set in Norfolk, easing a national shortage of donors.
See article below.

Pam Keeley, co-ordinator at the Norwich, East Anglian Eye Bank, works very closely with staff in the bereavement office at the Norfolk and Norwich Hospital. Staff in the bereavement office sensitively prepare relatives by introducing Pam to them after they have completed their own interviews. She always errs on the side of caution, to avoid further distress, only approaching relatives if the circumstances are entirely favourable.

Relatives are contacted by Pam at an early stage and the net result has been a 181% increase in the number of corneas being retrieved, giving Norwich one of the best records in Britain.

Pam said that taking the task of corneal donation away from already hard-pressed doctors and nurses meant that donation could be raised sensitively at a more appropriate time.

All corneas retrieved locally are currently sent to the CTS eye bank in Bristol for screening, processing and distribution; but many end up back at the West Norwich Hospital where they are used to restore the sight of patients under the expert care of consultant surgeon Peter Davies, Director of the East Anglian Eye Bank.

Mr Davies said that he believed that if three or four other large hospitals around the country followed Norwich's example, the severe shortage of corneas for transplantation would be reversed and the waiting list of patients for cornea transplants would be greatly reduced - and possibly even eliminated.

He said: “The success of the Norwich initiative has been so impressive that UK Transplant has recommended that the Department of Health considers contributing to the costs of up to five similar schemes around the UK.” Pam commented: “Following a successful corneal transplant operation, people can see straight away. It's fantastic for the patient who has lost their sight only to see it restored through the skills of good team working and the foresight of someone who has approved the donation. The success rate for a corneal graft is around 90 per cent. I have a hard job, but it's also very satisfying, knowing that I have been part of a process which has led to something positive coming from a sad event.” Once Pam has the go ahead for donation to take place, she retrieves the eyes surgically. A call giving relatives' permission could come at any time. She finds her work challenging, but extremely rewarding.

Raising the profile of cornea transplant throughout the hospital has also helped lead to an increase in other organs and tissues being donated through the Trust.

Susan Abbot, who spoke for the bereavement officers, said: “We work very closely with Pam as a team. Pam keeps us in touch with the cases in which donations are made, and although we have a rewarding job, this makes it more so”.

Pam Keeley, centre, is pictured with colleagues from the bereavement office. From left: Susan Abbot, Yvonne Smith, Karen Drake and Sally Fletcher

*This article first appeared in ***The Scanner***, the in-house newspaper of the Norfolk and Norwich Hospital. We are grateful for permission to reproduce it here.

NATIONAL EYE RETRIEVAL SCHEME

Encouraged by the success at West Norwich, the UKTSSA Users' Cornea Advisory Group set up a Reimbursement Scheme Task Force. Pilot sites were successfully established; based on their experience the Department of Health has agreed a one-year trial of a full National Eye Retrieval Scheme (NERS).

Under the new Scheme, four hospital sites will receive a contribution of £20,000 towards eye retrieval costs for one year during which they will be expected to retrieve a minimum of 400 eyes for deposit with the CTS Eye Banks. The four hospitals with this challenge are:

Queen Victoria Hospital,
East Grinstead

Royal Liverpool University
Hospital

Royal Victoria Infirmary
(with the Freeman Hospital),
Newcastle

West Norwich Hospital

In order to recognise and encourage other significant contributors to the CTS Eye Banks, a retrospective, flat-rate sum of £5,000 will be paid to those hospital units that have deposited 100 corneas in the previous year.

NERS will replace the former Cornea Reimbursement Scheme which was subject to annual fluctuations and could offer no guaranteed funding to contributing units. It is anticipated that the new Scheme will result in an increase in UK-wide retrieval rates.

David Smerdon
Chairman, UKTSSA Users' Cornea Advisory Group

See also the article above outlining the experience of West Norwich Hospital

UK National Transplant Database

Direct access to the new National Transplant Database is now possible from any PC (or laptop) by using new applications designed for NHSnet (Healthnet) or Internet connection. This facility is open to named users and strict password and security features apply.

This article gives a brief description of each of the new applications. Named users have been provided with manuals containing detailed instructions on how to access and use them. It should be noted that the applications do not provide access to the entire National Transplant Database: additional national and centre-specific information can be obtained from the Information Executive at UKTSSA on 0117 975 7555.

Patient Registration, Amendment and Follow-up

Using this application centres can:

register patients electronically (the screen looks similar to the current paper forms);

view individual patient registration forms;

amend any registration form as necessary;

report follow-up information (including that required for the Royal College of Surgeons' cardiothoracic and liver transplant audits);

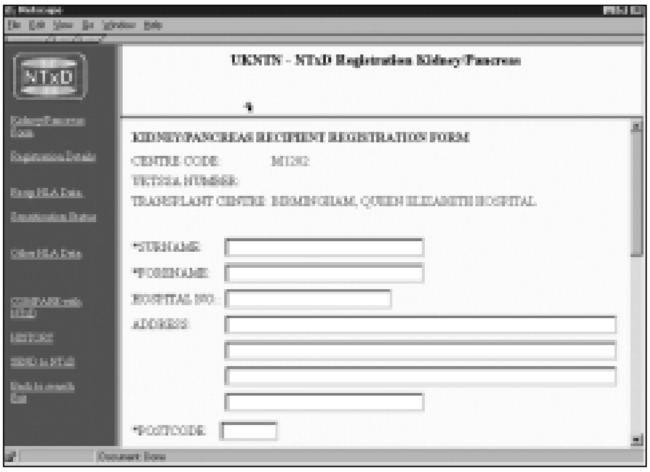
view data on an individual patient/form basis.

Online Statistics

The options available online are all password controlled so that centre-specific data can only be viewed by named personnel at the appropriate centre. The information is taken directly from the National Transplant Database and updated daily.

Designated users may request summary activity information specific to their own centre or region/zone, or nationally. Four options are available to view (transplant and donor summary data may also be printed or transferred to an Excel spreadsheet):

1. Transplant Summary - summary information from data relating to all solid organ transplants reported to UKTSSA since 1985 is available, specified as:



UKNTN - NTxD Registration Kidney/Pancreas

KIDNEY/PANCREAS RECIPIENT REGISTRATION FORM

TRANSPLANT CENTRE: BIRMINGHAM, QUEEN ELIZABETH HOSPITAL

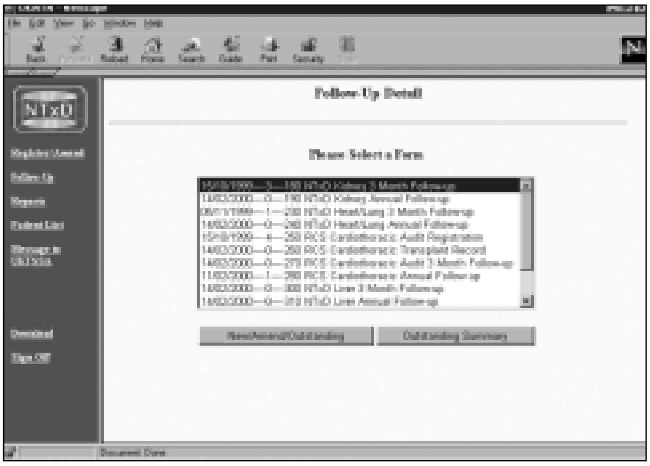
*SURNAME:

*FORENAME:

ADDRESS:

*POSTCODE:

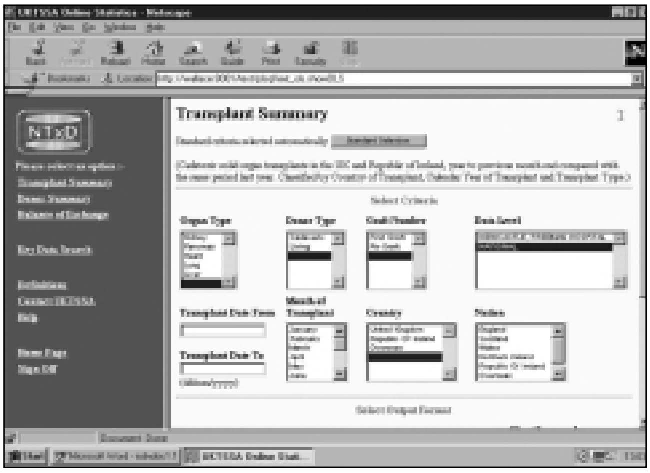
Patient Registration and Follow-up - Registration screen



Follow-Up Detail

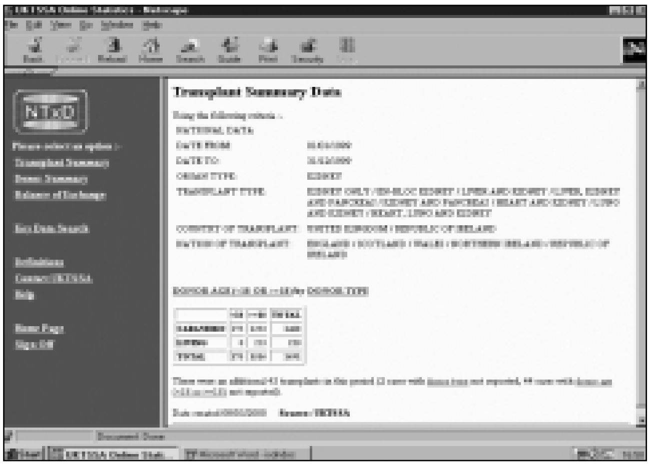
Please Select a Form

Patient Registration and Follow-up - Follow-up first screen



Transplant Summary

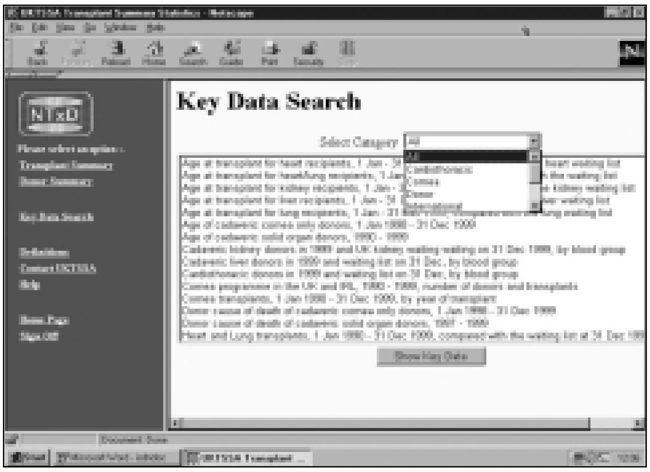
Online Statistics - Transplant Summary selection screen



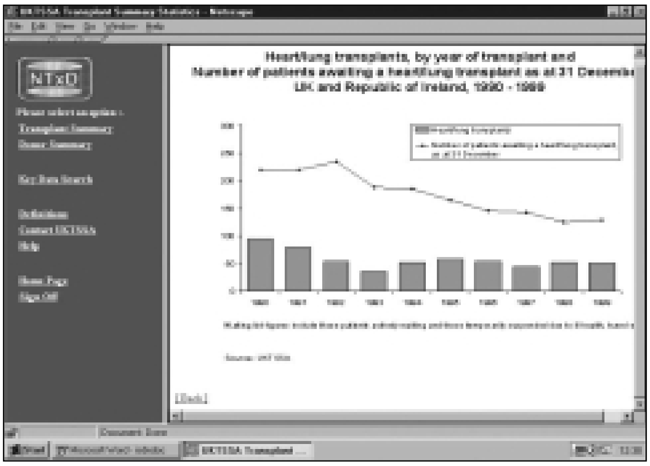
Transplant Summary Data

Online Statistics - Transplant Summary results

- new direct access for users



Transplant Summary Statistics - Key Data Search



Transplant Summary Statistics - sample chart

type of organ transplanted

type of donor

country where the transplant was undertaken.

The selected information can be tabulated into different categories: those currently available include year of transplant, region/country of transplant, sex, age, blood group, primary disease of the recipient, and sex, age, blood group and cause of death of the donor. Information can also be categorised by the graft number, HLA mismatches and organs exchanged.

Other categories will be added over time depending on user feedback.

2. Donor Summary - a similar option to that available for transplants but relating to donors reported since 1985. Again, it is possible to sub categorise. The information presented will provide donation levels for particular organ types over time and show changing age, blood group and cause of death distributions.

3. Balance of Exchange - providing the kidney balance of exchange at the beginning of each month.

4. Key Data - various graphs and tables from published documents which can be exported into other applications.

Centre-specific Data Download

Using this application centre-specific data held on the National Transplant Database can be extracted onto a user's own PC. Download in comma-separated variable (CSV) format will enable further data analysis to be undertaken locally. Transplant and Donor options are available. The Transplant option will allow transplants within a specific time frame to be specified, and data extracted on the recipient (age, blood group, primary disease, etc.), the donor (age, blood group, cause of death, etc.), the transplant (HLA mismatches, exchange of organ, etc.) and follow-up information associated with the transplant (last known date the transplant was functioning, cause and date of failure, cause and date of death).

The Donor option allows download of specific information for donors where organs were retrieved by the transplant unit in question.

Transplant Summary Statistics

In addition to those designed for use by transplant services, an NHSnet interactive application has been developed to provide national transplant summary statistics to the wider NHS, including managers and commissioning authorities. Options include specific solid organ transplant and donor statistics as well as static tables and figures from published documents.

Accessing the new Applications

Accessing these applications on a hospital site using a PC other than the dedicated UKNTN PC will depend on whether or not the PC to be used is connected to NHSnet/Internet through the hospital's own network. Local IT Departments should be able to advise on this. Additionally, Internet access is available using a PC or laptop at home or elsewhere. The minimum specification for PCs (whether networked or not, and whether laptop or not) is:

Pentium II 300Mhz or above, with 32Mb of RAM, Windows 95/98/NT (if using Windows NT a minimum of 64Mb of RAM is recommended).

Security and Authorisation

Security has been a major feature of developing these applications. All data transferred to or from UKTSSA electronically will now be encrypted. In addition, new secure access procedures have been introduced: only named users who have been authorised by unit Directors and who have been allocated a security fob and PIN number will be able to access the system. This authorisation procedure provides positive identification for each person using the system, regardless of from where they are connecting.

The Next Stage - We Need Your Feedback

A series of 'Roadshows' is being organised to provide not only transplant service personnel but others with an opportunity to comment on using the new software, and to make suggestions for new modules. Please use the applications, take the opportunity to attend a Roadshow and let us know what you think. In that way we can ensure that we continue to produce applications which meet the needs of the widest possible range of users.

David Shute
Director of Operations,
UKTSSA

From the Advisory Groups

Members of both the Users' Cardiothoracic and the Liver Advisory Groups noted the report (published in February) of an investigation into conditional donation by a Panel chaired by the Department of Health's Permanent Secretary. The Panel's recommendation that no conditions were acceptable when organs were donated had been endorsed by Ministers. If, after discussion with the donor family, conditions were still insisted upon, transplant co-ordinators would have no option but to decline the organs.

MSBT Guidelines

The draft revised guidelines from the Advisory Committee on the Microbiological Safety of Blood and Tissues for Transplantation (MSBT), were welcomed by members of both Groups as being less prescriptive. Any decision whether or not to use organs is a clinical one based on risk assessment for the individual patient; the only absolute contraindications to solid organ donation being donors who are either HIV positive or have CJD.

At the Liver Advisory Group members noted that the Advisory Committee had discussed the desirability of testing donors for hepatitis B core antibody: due to the potential for false positivity and the concern that such reports might preclude multi organ donations it had been agreed that organs could be transplanted even if tests were positive.

CARDIOTHORACIC ADVISORY GROUP

Urgent Heart Allocation Schemes

At their meeting on 21 March, Members considered a nine-month monitoring report on the adult and paediatric Urgent Heart Allocation Schemes introduced on 1 April 1999. Although initial use of the Schemes had been low, the desired outcomes appeared to have been achieved: a further review would be made in Spring 2001. Members agreed that because paybacks for adult hearts transplanted into urgent patients were made to the national pool rather than to the donating centres, the impact on individual units would be monitored.

Allocation of Paediatric Donor Organs

Donors of cardiothoracic organs are aged 14 years or under, while recipients are either under 16 years of age, or have a body weight of 30kg or less. In addition, small adults weighing 40kg or less may be registered as paediatric at a unit's discretion. Members reviewed these definitions and agreed that they should remain unchanged. However, UKTSSA would remind centres of the current definitions; centres that had not registered as small adults those patients who had met the criteria would be offered the option to do so; patients who did not meet the criteria would not be eligible for registration as such.

Members felt that small adults (as defined) should be part of the paediatric recipient pool and requested that UKTSSA formulate a protocol to adjust the paediatric rota to include those centres at which small adults were registered at the time.

Non-use of Cardiothoracic Organs

Members had been encouraged to note that, despite a drop in the number of potential donors, the number of heart/lung and lung transplants had risen during 1999. Nevertheless, they were concerned that the reasons given for non-use of cardiothoracic organs should be recorded accurately. They were particularly concerned to know the circumstances of those potential - but eventually unsuccessful - donors who were not reported to UKTSSA, so that their details were not available for analysis through the National Transplant Database. Members felt that an audit of such potential donors would be useful, and that the task of data collection could best be carried out by Transplant Co-ordinators with analytical assistance from UKTSSA. A Task Force will be established to consider the required data set and data collection strategy.

Organ Offers

Members confirmed that organs offered to other centres should not subsequently be withdrawn by zonal teams: all offers, including those from zonal donors should be accepted or declined within 45 minutes. There would continue to be no formal 'compassionate' category and no deviation would be made from the offering sequence for such cases.

The fast track offering scheme was to be used only for organs that were exceptionally available at short notice. UKTSSA will monitor the reasons why cardiothoracic organs are offered in this way and Members will review the situation at their next meeting.

Data Follow-up and Collection

Members welcomed UKTSSA's initiative to improve data follow-up by increasing the support given to units as reported in the last *Users' Bulletin.* The scheme's aims are to assist units with the completion and transmission of follow-up data; to assist with data collection for specific register, study and research initiatives, and support validation for the Royal College of Surgeons.

National Specialist Commissioning Advisory Group

Members of the Cardiothoracic Advisory Group noted that Ministers had accepted a recommendation from NSCAG that a pulmonary thromboendarterectomy service be designated and centrally funded from April 2000, initially from a single centre (at Papworth Hospital). Further consideration would be given to the requirement for a second unit.

NSCAG also considered there to be a case for a controlled evaluation of the role of left ventricular assist devices (LVADs) for young adults with cardiomyopathy. A second evaluation would consider the use of pulsatile ventricular assist devices as a bridge to transplantation in younger children with dilated cardiomyopathy. Members were concerned about the potential impact on the transplant programme and would await the proposed protocol.

Following the Royal College of Surgeons' Report[1] recommendation that a minimum one in four rota should be the norm in transplant centres, a study had been commissioned: NSCAG and Health Minister Lord Hunt had agreed that criteria should be set for all transplant units.

Members were concerned that with the current availability of donor organs the number of designated transplant centres might reduce; they awaited a draft report from NSCAG.

[1] Report of the Working Party to Review Organ Transplantation, Royal College of Surgeons, January 1999

From the Advisory Groups

LIVER ADVISORY GROUP

A major item of discussion at the UKTSSA Users' Liver Advisory Group on 9 May was a modified organ allocation scheme. Members recognised the need to ensure that donor organs were allocated in a fair and transparent way. Professor Peter Friend presented a proposed scheme which aimed to address equality of access to donor organs and diminish the requirement for annual negotiation of the zonal system. The proposal was for organ retrieval to remain the responsibility of zonal teams, although donor livers would be allocated to centres on the basis of a points scoring system. Simulations had been run from national Transplant Database information to assess potential schemes. That proposed allocated points based on contract size, distance of donor to transplant unit, contract activity ratio and waiting time: the donor liver would be allocated to the highest scoring centre. Members agreed to discuss the proposal with colleagues within their units and to report views to Professor Friend: an amended Scheme will be considered by Members at their next meeting, in November.

There was general agreement that the super urgent allocation scheme for livers worked well and should be maintained.

Non Heart Beating Donors

Members heard that successful transplants of livers from non heart beating donors had been reported from Spain and that Health Minister Lord Hunt was enthusiastic that organs from all potential donors should be explored. A national protocol for non heart beating donors would need to be developed and Members affirmed the need to ensure that recipients were fully appraised of risks associated with donor organs whether from heart beating or non heart beating donors. In the UK, both the Freeman and King's College Liver Transplant Units were working with Renal Unit colleagues to evaluate potential non heart beating liver donors.

Liver Transplant Waiting Lists

Following their previous meeting, Directors of Liver Transplant Units had worked with UKTSSA to review the liver transplant waiting lists. The Department of Health had advised Directors that careful consideration should be given to the acceptance of referrals from overseas. Units receiving such referrals would need to consider the individual patient's needs against the needs of the local population and any specialist local skills that were available to treat rare clinical complications.

Donor Information

Members were aware that donor livers declined by one unit as being unsuitable for transplant might be accepted by another unit and successfully transplanted. For this reason, they considered it crucial for transplant co-ordinators to collect detailed information about each donor and pass it on to UKTSSA when organs are offered. An on-going audit of the use and outcome of livers from marginal donors would be kept under review.

Use of Split Livers

Liver transplant centres were encouraged to consider splitting livers, on a voluntary basis. Initially one lobe would be used for children; however, Members hoped that in the future both lobes could be successfully transplanted into adults. Exchange of whole livers for suitable lobes would also be encouraged.

Laraine Joy
Head of Advisory Group Executive

MERRY HILL FASHION AND HEALTHPOINT LAUNCH ORGAN DONATION CAMPAIGN

Healthpoint, the Regional Health Information Service, and Merry Hill, a fashion house, have teamed up with the West Midlands Health Authorities to raise awareness on Organ Donation.

In support of events at the two-day Healthpoint Organ Donation Awareness Campaign on 27 and 28 April Merry Hill staged one of its renowned Fashion Live Events - a special one-off fashion show entitled 'New Kids On The Block'. Children from around the Region who had received an organ transplant took part as models for the day in the professionally produced show which presented new fashion statements for the season ahead.

The children's show launched a Region-wide poster campaign showing two young children - one who had been successfully transplanted, and one on the waiting list for a transplant.

The posters have been described as “heart wrenching, yet joyful”, by Geoff Watkins, Manager of Healthpoint.

Beverley Cornforth, the West Midlands Transplant Communications Manager who has co-ordinated the Campaign with Healthpoint, says:

"These children are a tribute to donor families and to the success of transplantation in this region, without which many of them would not be alive today. It's thanks to organisations like Merry Hill Fashion Live and Healthpoint that we are able to raise public awareness of the need for transplantation and to encourage people to discuss their wishes with those closest to them."

The children taking part in the Fashion Show come from Selly Oak, Coventry, Wolverhampton, Shirley, Magley, Coleshill, Sutton Coldfield, Kingswinford, Shrewsbury, Malvern, and Handsworth Wood.

For further information on Organ Donation, Healthpoint can be contacted on freephone 0800 665544.

Beverley Cornforth
West Midlands Transplant Communications Manager

Jordan Wiggan (left, aged six, kidney transplant) and Troy Charles (right, aged six, kidney transplant) with one of the models

Transplantation **Cardiff 2000**

The Opening Plenary Session of the British Transplantation Society (BTS) 3rd Annual Congress, held in the impressive Cardiff City Hall, was devoted to viral infection and therapeutic strategies in transplant patients.

Professor Borysiewicz described the evolution of CMV defences against cellular attack. Firstly, CMV blocks the normal assembly of HLA Class I molecules to evade CD8 cytoxic T cells. Secondly, it avoids the NK cell killing of cells deficient in HLA Class I by loading HLA E molecules directly with CMV peptides, in place of the usual processed peptides from HLA Class I leader sequences which are the usual NK cell targets. CMV has found a natural balance between host and virus, as it is relatively harmless in fit people. When asked whether CMV negative transplant patients might benefit from deliberate CMV infection, Professor Borysiewicz replied that it was probably too risky to be considered.

Peter Amlott summarised the severe risk of lymphoma in EBV negative immunosuppressed patients (several hundred times the risk in the normal population for Heart/Lung recipients). Therapy could consist of antiviral drugs or reduction of immunosuppression to allow the EBV specific cellular responses to recover. The reduction in immunosuppression could be rapid, or tailed off at a slower rate. The results were impressive and showed that the slow reduction in immunosuppression monitored by FACS analysis was the superior therapy. The conclusion that post-transplant lymphoproliferative disease indicates over immunosuppression, was reported by several speakers during the conference.

In the afternoon, Barry Kahan reported on the monitoring of immunosuppression levels and reminded the audience that individual patients have different absorption and clearance characteristics, black patients especially having a lower bioavailability. Neoral was absorbed better than cyclosporin A. He believed that a single four-hour blood measurement was sufficiently predictive of drug bioavailability in an individual patient.

Dr Danovitch explained that FK506 and cyclosporin were both very good drugs and choice may now be made between the known side effects. For instance, teenagers may prefer the least disruptive cosmetic effects of Tacrolimus even though it may be slightly more nephrotoxic. He also warned that the increasing number of tumours could take back the gains made by the improvements in immunosuppression, so dosage was very important.

Turning to pharmokinetics and synergy, Dr Kahan explained that Rapamycin was a G1 Phase inhibitor and effective in combination with the calcineurin inhibitors; it enables the dose of cyclosporin, for instance, to be reduced by up to 50%. Rapamycin reduces rejection episodes, it has effects on the cholesterol and triglycerides levels but the white cells and platelets are OK. He believes it signals the dawn of a new era in immunosuppression.

In the following session Dr Kahan reviewed the new immunosuppressive drugs on the horizon. The new agents were targeted on T cell signalling and homing (FTY720 - described in 1966!), on activation of adhesion molecules (ICAM antisense) and through cytokine activation and signalling.

Bert Kasiske reported that in long-term kidney transplant studies, acute rejection episodes within the first three months were relatively harmless but beyond six months were highly correlated with graft failure. On histology, vascular rejection was serious compared with interstitial cellular rejection. He noted that treatment of biopsy proven rejection gave better creatinines, two years later than no treatment; he therefore encouraged all centres to undertake protocol biopsies.

Dr Kesh Baboolal reinforced the value of protocol biopsies at 0, 1, 2 and 3 months because it gives a superior indication of the need for steroid treatment than creatinine or creatinine clearance. CD68 staining of slides can also reveal the type of rejection and the type of infiltrate.

The following day, Mike Nicholson reminded the audience that interstitial fibrosis "the pink stuff in the slides", is collagen accumulation resulting from a healing process which has become unregulated. Essentially there is a failure of collagen degradation associated with the action of TGF. He was encouraged by the role of Rapamycin in down regulating the fibrogenic agents.

Continuing the theme of tissue damage Neville Jameson reviewed the development of organ preservation fluids, with various buffers, metabolites reducing agents and impermeants included to address the problem that not all tissue organelles lose function at the same rate. Machine perfusion is now making a comeback, with UW Gluconate as the preferred medium for non heart beating donors.

Dr Danovitch spoke of the criteria to join the transplant waiting list in Los Angeles. Recipients are screened for smoking cessation and for hepatitis (which must be treatable with antivirals), obese patients are encouraged to lose weight and patients with covert coronary artery disease are offered surgical repair before joining the transplant list.

Up to 30% of renal patients are transplanted with LRD organs without joining the waiting list and overall up to 35% of transplants are from LRD donors (compared with 14% in the UK). Dr Danovitch encouraged UK units to pursue this route and also commended the use of ULTRA donors to meet the organ shortfall.

Professor Robert Lechler, in investigating tolerance, showed by limiting dilution assays that even in chronic rejecters there is a low frequency of IL-2 producing HTLp cells directed against donor target cells. But the use of cell fragments to load the indirect pathway in presenting cells did succeed in demonstrating higher frequency to donor than to third party cells in chronic rejecters. The graft is instrumental in inducing the unresponsiveness. Is it anergy or deletion?

In a rodent model the transfer of anergic T cells which protected transplanted skin seemed dependent on cell to cell contact causing a lowering of HLA-DR and the B7 isoform in the host dendritic cells. Professor Lechler speculated that such modified dendritic cells may have a modifying effect after migration to lymphoid areas.

Bert Kasiske and Professor Williams enlarged on the cardiovascular risks. In Minneapolis 50% of transplanted patients had cardiovascular disease in the 15 years post grafting. Dr Kasiske encouraged regular screening every two years for cardiovascular disease. Professor Williams' message was that there was no safe target for blood pressure (BP) control: even small reductions in BP resulted in lower risk, so BP should be maintained as low as possible. The main problem was drug compliance and the major task was to prescribe medicine which patients could tolerate in the long term.

Dr Cunningham reviewed the risks of osteoporosis post grafting where nearly 7% of bone mass is lost within six months and fractures are not uncommon, especially in females. Azathioprine and MMF seemed to be neutral, while cyclosporin and FK do result in bone loss. To protect bone post grafting, some physical activity, fluoride, calcium and vitamin D were beneficial, while possibly two single doses of Pamidronate can help prevent initial bone loss.

Adam Jurewicz presented data on an impressive cohort of local patients starting in 1996 and comparing Neoral and FK therapy. A series of comparisons indicated the strengths and weaknesses of both drugs. The quality and completeness of the data was a tribute to the dedication of the Cardiff team. FK was the most effective in four years (87% vs 77% Kaplan-Maier) graft survival analyses. In other cases - de novo diabetes for instance - Neoral was superior, whilst in cardiovascular disease - and cholesterol for instance - there was no difference between the two drugs.

The conference closed by looking into the future. Professor Kathryn Wood summarised the approaches to gene therapy and reviewed the vectors currently under investigation. There are still problems to overcome: the production of immunogenic peptides, integration which is somewhat random and no organ specific vector has yet been found. A strategy is needed to place this work in a clinical setting with real problems; an opportunity in the field of stem cell biology is opening up which will require effective scientific and clinical expertise.

Dr Knechtle, from Madison, Wisconsin, reported on the delivery of CRM9 modified diphtheria toxin conjugated to a CD3 monoclonal antibody as a T cell depleting agent. It worked well as a tolerogenic agent in animal experiments if given seven days before transplant but was not so effective when given with immunosuppressive drugs on the day of transplant. The same seemed to be true in CD40 - CD40L blocking experiments where the 5C8 antibody gave good control of rejection, but when additional immunosuppression with steroids was given the results were worse. Early human trials with CD40L antibody (Antoma) had not been as good as the animal model, giving thrombotic effects and not controlling rejection.

The debate supporting "opting out" was conducted in friendly spirit with much style and cogent arguments on both sides, though not many minds were changed. In the vote the scientists were "gung ho" (to quote the Chairman) for the motion; the clinicians were equally balanced, while co-ordinator/nurses clearly rejected the motion. Interestingly, the Parliamentary debate a few days later produced a vote similar to that seen among the scientists - what does that prove about MPs or scientists?

Thanks are due to Richard Moore and his enthusiastic team for making all the delegates feel very welcome, and for organising another highly successful BTS conference.

Terry Ray
Head of Laboratory Services,
UKTSSA

UKTSSA Contribution

At the Cardiff BTS, UKTSSA Statistical Staff presented four papers and two poster abstracts which are briefly outlined below. Further details of the analysis presented can be obtained from the Statistical and Audit Services Division at UKTSSA.

The UKTSSA stand in the exhibition hall attracted a steady flow of visitors who saw, first hand, demonstrations of the new web based external user applications. Patient registration and amendment of patients' records and confidential reporting of patient follow-up can now be achieved from almost any computer equipped with a modem and authorised access in each centre. Data quality is a constant plea from those advising UKTSSA on analysis and audit. The demonstrations at Cardiff show the way forward for ensuring data transmission, in addition to the benefits gained from secure access both to centre-specific and national information. (For details of the individual applications see page 3 of this Bulletin.)

New UK National Kidney Allocation Scheme: a review of the first year

Paper presented by Rachel Johnson

The presentation reviewed results of the first year in terms of HLA matching, points scoring factors and transplant survival. Potential problems with the Scheme were also briefly discussed. The most important impact of the new Scheme has been significantly to improve HLA matching results for both adults and children. The proportion of 000 mismatched grafts increased from 7% to 13% in adults and from 2% to 11% in children. There has also been a 38% increase in the number of highly sensitised patients receiving 000 mismatched grafts. Improved HLA matching is a result of greater exchange of organs but there has been no significant increase in mean cold ischaemic time.

44% of adult kidneys were allocated through the Scheme; in 73% of these cases points scoring was required to prioritise potential recipients. No significant effects of points scoring factors have become apparent in the transplant pool. However, as might be expected, post transplant survival of the cohort would appear to be

cont. on page 10

significantly improved at three months compared with grafts in the years 1994-1996.

Potential problem areas were identified, the first of which was Balance of Exchange. Some centres continue to extend the extremes of positive and negative Balance. This is a complex issue confounded by varying centre/alliance practices. The UKTSSA Users' Kidney Advisory Group have asked Mr Chris Rudge to chair a Task Force to investigate and make recommendations.

The excess of HLA-DR homozygous patients on the waiting list was also considered. 22% of the waiting list at January 2000 were HLA-DR homozygous compared with only 14% of donors (1996-1998). This is a result of many years of using homozygous organs more often in heterozygous recipients than homozygous ones. At their meeting in January 2000, Renal Unit Directors agreed to amend the National Kidney Allocation Scheme with effect from July 2000 so that HLA-DR homozygous patients are prioritised for HLA-DR homozygous donors.

Liver graft failure and retransplantation in the UK

Paper presented by Mark Belger

This paper reported on a recent study of the reasons why first cadaveric liver transplants failed and the type of failure that results in a regraft. The outcome of retransplants in terms of one year transplant survival was also considered. The analysis showed that technical failures, failures from primary non function and hepatic artery thrombosis, were the main reasons for the early graft failure (designated as failing within 14 days). Late failures were due to chronic rejection and recurrence of disease.

The cause of failure, and not the time to failure, affected the chance of a patient being retransplanted. Technical early failures and recurrence of disease for late failures resulted in the death of the patient, while early failure due to primary non function or hepatic artery thrombosis and late failures due to chronic rejection, resulted in the patient generally receiving a second liver transplant.

Homozygosity on the national kidney transplant waiting list

Poster

Following requests from the UKTSSA Users' Kidney Advisory Group, this work focused on the 8% excess of HLA-DR homozygous patients on the UK kidney transplant waiting list (22%, compared with 14% of donors) and the options for improving the situation. An analysis of the waiting list showed that HLA-DR homozygous patients had a longer median waiting time than their heterozygous counterparts. Kidneys from HLA-DR homozygous donors were also shown to have been transplanted into 000 mismatched heterozygous patients, highly sensitised patients and children. Only 25% of all kidneys from adult HLA-DR homozygous donors were transplanted into HLA-DR homozygous recipients.

Simulation modelling was used to assess the effect of altering the National Kidney Allocation Scheme to give some priority to HLA-DR homozygous patients. Renal Unit Directors agreed a revision to the Scheme at their meeting in January 2000 which will be implemented in July. Details of the changes can be found in the Spring edition of the *Users' Bulletin* (Issue No 35, page 4).

Comparisons of one year transplant survival provided the following survival estimates and 95% Confidence Intervals (CI):

First Grafts	79% one year transplant survival (95% CI, 76-81)
Regrafts	59% one year transplant survival (95% CI, 51-67)

Considering Regrafts only:

Early Regraft	47% one year transplant survival (95% CI, 33-61)
Late Regraft	64% one year transplant survival (95% CI, 55-74)

Further work is now required to investigate why regrafts following early first graft have poorer transplant survival than those following late failure.

Small adults - are they disadvantaged in liver transplantation? -

Poster

A study for the UKTSSA Users' Liver Advisory Group looked at whether patients defined as 'small' adults were disadvantaged under the national liver allocation scheme in the UK. In summary the analysis looked at two definitions of small adults: adults weighing 45kg or less and adults weighing 60kg or less. These two groups were compared with both heavier adult and paediatric patients with regard to median waiting time, deaths on the waiting list and one year transplant survival. It was found that small adults weighing 45kg or less had a longer median waiting time than paediatric patients; that under either small adult definition they had a higher proportion of patient deaths compared with paediatrics and other adults, and that their one year transplant survival rates were lower, although not statistically significantly so. Following discussion of these results the UKTSSA Users' Liver Advisory Group introduced a small adult registration scheme for patients weighing 45kg or less, giving them a similar priority to children.

Factors affecting the waiting time to kidney transplant in the UK

Paper presented by Mark Belger

This paper looked at the factors found to influence the time a patient waited for a kidney transplant. Full details of the work undertaken can be found in the forthcoming Renal Transplant Audit. All registrations on to the national kidney transplant waiting list between 1990 and 1997 were considered - 17129 adult and 1060 paediatric registrations. Adult and paediatric patients were studied in separate multifactorial models. For adults, blood group, patient gender, age, year of registration, diabetes, the number of previous grafts and HLA-DR homozygosity were all found to be highly significant factors affecting waiting times to transplant. For paediatric patients, blood group, the number of previous grafts and HLA-DR homozygosity were the only Liver Advisory Group factors found significantly to influence the time to transplant. An analysis of adult regrafts showed that in addition to those factors found to influence the time to first graft, the number of HLA-A, B, DR mismatches and survival time of the first transplant were significant factors influencing time to regraft.

In summary, the analysis of kidney registrations found that waiting times have increased in recent years: blood group O and B patients, older patients, female patients, diabetics and HLA-DR homozygous patients waited longer, while patients with previous kidney transplants waited significantly longer. The time patients wait for a second kidney transplant is additionally influenced by the number of HLA-A, B, DR mismatches and the time to failure of their first graft.

National allocation of cadaveric kidneys to children in the UK

Paper presented by Rachel Johnson

This paper was presented on behalf of the UKTSSA Users' Kidney Advisory Group Paediatric Task Force and looked at the issue of HLA-A, B, DR matching in children. Matching results are inferior to those achieved in adults although the reasons for HLA matching are at least as important: first, to minimise sensitisation for future graft requirements, secondly, to improve post transplant survival. Ways in which improvements in HLA matching in children have been achieved over the years were revisited. The effect of the new National Kidney Allocation Scheme has been significantly beneficial for children: 49% of grafts 000 or favourably matched compared with 35% previously. This has been achieved through greater access to national adult kidneys. Following this change, computer simulations were undertaken to assess the effect of improving further the number of favourably matched transplants in children. Results of the simulations showed that the proportion of favourably matched transplants could be increased from 38% to 43% by offering the second kidney from an adult to a national favourably matched paediatric patient preferentially over a local favourable adult. This change would result in 0.4% fewer adult transplants. The proposal was accepted at the Renal Transplant Unit Directors' meeting in January and will be implemented in July 2000. Further details of these changes can be found in the Spring edition of the *Users' Bulletin* (Issue No 35, page 4).

Mark Belger
Head of Statistical and Audit Services Division, UKTSSA

UKTSSA LABORATORY SERVICES RELOCATION

The final pieces of the strategy are now in place to close the laboratories at Fox Den Road and to relocate the services to alternative providers. Final transfer dates are still a little uncertain as some contractual details have to be resolved and some accommodation has to be refurbished. But the overriding aim has been to ensure a smooth transfer, with an uninterrupted service to users.

The DNA control kits and cell line service is fully operational at NIBSC, Potters Bar, and the UK NEQAS for H&I is fully functional at the Welsh Blood Service, Cardiff. However, samples and enquiries for HLA reference work should continue to be directed to UKTSSA until the service transfers to the National Blood Authority, Bristol Centre at the end of June.

UKTSSA will not longer be providing a local tissue typing service for the Richard Bright Renal Unit. Mary Younie and the team who have supported the Unit for many years will be transferring to the North Bristol NHS Trust to provide the service direct in future.

Service	Provided By	Details	Contact Details
Scientific Adviser	Dr Susan Fuggle	As now, at UKTSSA on 2½ days per week.	UKTSSA - 0117 975 7504
Support for Duty Office, dealing with HLA nomenclature and sensitisation advice	Mrs Linda Shelper Mrs Elizabeth Bidwell	As now, at UKTSSA. Linda and Liz have transferred to the Data Executive and will continue to support Users and UKTSSA staff with HLA enquiries.	UKTSSA - 0117 975 7449
HLA Sequences updates	Dr Stephen Marsh	As now, HLA sequences are updated every 3 months, and the files made available to Users over the secure NTN link.	Linda Shelper UKTSSA - 0117 975 7449
UK NEQAS for H&I	Dr Chris Darke Mrs Susan Corbin	The service is up at the Welsh Blood Service, Cardiff.	WBS Cardiff 029 2062 2185
DNA control kit supply, Cell line banking	Dr Glyn Stacey	The DNA control kits and cell line catalogue are now managed by NIBSC. Materials will be supplied to NHS Users free of charge until 2002.	Dr Glyn Stacey, NIBSC, Potters Bar, South Mimms, Herts Telephone 01707 654753 Fax 01707 646730
HLA Reference Services			
1. Routine HLA sequencing	Dr David Briggs Dr Paul Dunn Mrs Sarinder Day Miss Claire Brazil	To be based at the NBS, Bristol. To undertake sequencing to resolve HLA typing problems and to provide contract services to UK NEQAS for H&I and NIBSC.	NBS, Bristol - 0117 991 2125
2. Method development	Dr Ken Welsh Dr Mike Bunce	To be based at the Oxford Transplant Centre to explore new techniques and genes of potential relevance to organ transplantation.	Oxford Transplant Centre 01865 226102

This article argues that the scarcity of social research in transplantation and the prioritisation of scientific knowledge over experiential knowledge have contributed to the rather narrow conceptualisation of 'donor shortage' solutions over the years. The argument is not against the need for and the use of quantitative methodologies but suggests that these strategies do not always provide the most appropriate method for obtaining information. Indeed accrediting experiential knowledge and actively encouraging a more comprehensive approach to research may prove enlightening.

At this juncture I should declare my interest and place myself firmly in the text, which immediately distances me from the objective and detached researcher that many accept as the hallmark of good research. Since 1984 and until recently, I have worked as an organ donor co-ordinator, a role which has immersed me in the reality of death, dying and the struggle to make sense of the somewhat bizarre and macabre concept of deconstructing dead bodies and reforming others. During this time there have been significant influences that have informed my thinking, biomedical, bioethical, psychological and social. However, the most influential has been through my lived experience of the narratives of hundreds of bereaved families, as well as the accounts of doctors, nurses and others caring for organ donors. It is this 'lived experience' (which I have in common with other transplant co-ordinators) that I consider of relevance and importance to the transplant community. It is through prolonged contact and exposure to bereaved individuals that attitudes, beliefs and understandings towards death, the body and organ donation are revealed. Yet it is this very type of knowledge, often perceived as anecdotal and therefore dismissed, that clarifies what is possible and what is desirable. In consequence, an understanding of the processes involved in organ donation is more likely to be collective with ICU colleagues.

This shared knowledge is evident from the way in which co-ordinators have, since the early days of co-ordination, been so often in harmony with intensive care colleagues and at odds with the transplant community, in particular over proposed solutions to increase the number of donors. For example, both the Intensive Care Society and the United Kingdom Transplant Co-ordinators Association have been against elective ventilation and presumed consent legislation. This dissonance is of crucial importance and yet few individuals have sought to ask the reasons, Why? despite the assumption that transplant co-ordinators have a common goal 'to increase the number of donors available for transplantation'. Whilst there is an understandable bias in the transplant community towards adopting strategies that are seemingly successful in other countries, the debate is rarely informed by 'local' knowledge.

I do not intend to imply that 'the transplant community' is a homogenous group. Of course there are clinicians with insight and understanding, but it also clear that many others have little awareness of the complexity of donor issues - which begs the question, how can informed debate take place without an understanding of the meaning and significance of the processes involved for the people implicated in the procedures? It is therefore in this area that qualitative research is urgently needed.

There is growing recognition that the establishment of an evidence-based medical culture depends on contributions from across research traditions and disciplines that can complement clinical practice (Savage 2000). The term 'qualitative' research is broad and covers a number of different approaches. It is not possible within the constraints of this article to detail the epistemological and ontological premises that inform particular qualitative positions. However, in general, qualitative research aims to generate data which gives authentic insight into people's experiences. The data can be obtained using a number of methods but is commonly through the use of open-ended interviews based upon prior, in-depth participant observation (Silverman 1993). Patricia Franklin's research in Oxford is an excellent exemplar. Moreover, this type of research seeks to be contextual, reflexive and derived from the point of view of those being studied. Implicit is the assumption that informants are active in the research, not merely passive participants in the research process. However, I do not intend to imply that qualitative research like other research is without its limitations. (See Skidmore 1979, Silverman 1985, Blaikie 1993, Hammersley 1995 for further discussion.)

Qualitative research is an anathema to many trained in the concept of objectivity. In the objective tradition research is conducted from the point of view of the researcher's conceptual and theoretical frameworks. The interviewee's concepts and meanings are either ignored or intentionally rejected and any hint of subjectivity on the part of the researcher is to be deplored. Thus it is clear that whatever research strategy we invest in, its methods are derived from competing paradigms based on quite different conceptions of the purposes and nature of social research. Even accepting this premise, I believe it is essential that both methods coexist. Transplantation is embedded in a complex web of intimate and attached relationships, which defy objectification and detachment.

Unfortunately most co-ordinators are grappling with the enormity of on call commitments and considerable workload which even for those with research training impedes many from undertaking formal research. (I am not suggesting that co-ordinators have never undertaken research, but that it is relatively rare given their expert status in donor issues.) However, even when good qualitative research is completed (Morgan 1999) there is no guarantee that the work will find a forum in the British Transplantation Society. This is perhaps understandable given that the BTS is primarily a scientific meeting for which abstracts need to conform to 'scientific' standards. Sociological and anthropological abstracts do not in general fit these criteria. That is not to suggest that qualitative work does not have to fulfil recognised criteria (Hammersley 1995, Denzin et al 1994).

Current social research in Oxford is underpinning the planning for future live donation programmes, thus demonstrating the potential for social research to be beneficial. Qualitative research should complement quantitative research and offer humanistic answers to some of the more complex clinical, psychosocial issues. Therefore, it deserves to be conveyed and supported in the field of transplantation.

In conclusion, I would ask you to consider how qualitative research, centre based and collaborative, might be encouraged and facilitated, and in addition how this might be disseminated. Perhaps then we might begin to see an end to the present circular debates on proposals to end the 'donor shortage'.

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Alison Crombie
(former Transplant Co-ordinator)
Europa Bioproducts Ltd

THE ASDA GREAT NORTH MILLENNIUM BRITISH TRANSPLANT GAMES 27-30 JULY 2000

In the tropical heat of a northern summer it will all happen. The streets of Tyneside will reverberate with the pounding feet of hundreds of transplant athletes striving for peak condition for their next day's competition. After nightfall the discos and nightspots will jump with the beat of the selfsame athletes relaxing after another series of sporting triumphs. And maybe late at night the balmy waters of the river Tyne will discreetly witness an occasional kiss and cuddle between athletes overcome by the seductive magic of the northeast. In other words the 23rd or Great North Millennium British Transplant Games are coming to Tyneside.

Our sponsorship seems to be progressing well. Asda are title sponsors and we look forward to working with them, not only to promote our Games but to promote transplantation and organ donation. We have many other plans for fund raising and are most fortunate to have the enthusiastic support of Nissan in Sunderland, in whose premises our Games office has now opened. In February we ran a Sportsman's dinner at Newcastle Civic Centre which attracted more than 350 people. Our fund raising includes the raffle of the 2 millionth Nissan to emerge from the production line, generously donated to us by the company. It is a very attractive Nissan Micra in light green which some lucky person will win and which hopefully will raise a lot of money towards running the Games.

The organisers hope that the games will be the largest ever which will mean attracting 750 competitors. With these being a very special transplant games we secretly hope for 1000 competitors plus their families to support them. Normally 20% of the competitors are children and for only the second year recipients of bone marrow allografts are allowed to compete.

The core events of all transplant games are athletics and swimming. There are racquet sports: tennis, badminton, table-tennis and squash. There is volleyball, bowls, golf and cycling. In all events where age may be a handicap there are medals in four different age groups. For those interested in less strenuous competition there is snooker, darts and ten-pin bowling. There is a full and varied programme for the children which is a mixture of sport, fun events and outings to theme parks, such as Beamish Museum and Washington Wildfowl Park. Normally the local committee has discretion to add special events to a programme which reflect local interests and facilities. However, specially for the Millennium Games we have permission from the TSAGB to incorporate more than the two discretionary events usually allowed. We therefore plan to have sailing, canoeing, archery, fishing and driving skills events as well as all the events normally associated with our Games. We expect this will add to the overall interest for everyone. The Sunderland Winter Sport complex has offered to make the ski slope and ice rink available to all participants at the games, who wish to try their skills.

Everyone attending the games will be accommodated in hotels. We have negotiated excellent packages in quality hotels and from these discount prices we will subtract something by utilising some of our sponsors' money to give a great deal to the competitors.

A full social programme has been arranged with a limited attendance at the Civic Reception on Thursday evening, when the opening ceremony will take place. An alternative social event has been arranged for that evening because everyone cannot be accommodated at the reception. On Friday and Saturday we have supper disco parties with live entertainment. We plan separate Gala events on Sunday for adults and children. We did this previously and it was enormously successful. Even with this separation we anticipate well over 1000 at the adult event.

All members of our local organising committee look forward to a memorable Millennium Games.

R M R Taylor
Chairman Local Organising Committee
Games Office contact:
Telephone: 0191 415 2590
Fax: 0191 415 2001

A Different Kind of Grief

- the experience of families of organ donors

This research was carried out as part of an MSc study in Social Research at the University of Surrey supervised by Hilary Taylor.

Aim

The purpose of this study was to assess, from a sociological perspective, the impact of organ donation on surviving relatives. There was no specific aim to investigate issues that may affect consent rates for organ donation. However, achieving a better understanding of the experience of donation for families will serve to inform healthcare professionals. This is important for both those who care for the potential donor and those who are helping a recipient reconcile the death of the donor with their own need for a transplant.

Methodology

Unstructured interviews were carried out with a purposive sample of 14 relatives of organ donors. For the purposes of comparison families were included whose relatives had died from natural causes or trauma and where the surviving relative was a spouse or a parent. Following permission from relevant Research Ethics Committees respondents were recruited through one group of Regional Transplant Co-ordinators. The study examined in-depth the relatives' experiences of understanding the moment of death; the way in which respondents described the donation; and the way in which the donation influenced the grieving process and what happens after the death. The interviews were audio taped and transcribed. Analysis was achieved using the grounded theory approach with the intention of generating theories and concepts by the process of constant comparative analysis of the data.

Analysis and Interpretation

Three important themes emerged from the data that were explored. Firstly the conflicts arising from accepting a medical construction of death and then reconciling this with the social construction. Secondly the process of depersonalisation of the dead donor, both at the time of the donation manifested by the prevention of the removal of some organs or tissues, and in the acceptance of the status of the recipients. Finally the support or hindrance to the grieving process.

Reflections and Conclusions

This descriptive study of the experiences and feelings of the families of organ donors has highlighted some important issues surrounding the understanding of death and the meaning of the donation process. The demand for organs for transplantation has meant that the attitudes and conceptions of people regarding the disposal of their own bodies, and those of their relatives after death, are no longer a private affair. These attitudes and beliefs are now influenced by health care policies and legislation. Such influences will have consequences in the social understanding of bodies, death and giving.

Vanessa Morgan
Regional Transplant Co-ordinator, North Thames

OVERSEAS REFERRALS

In February 1996, the NHS Executive issued Directions about the allocation of human organs for transplantation. These advised that decisions about individual cases must be made locally, based on the circumstances of each particular case.

More recently, further clarification has been obtained from the NHS Executive specifically in response to requests from liver transplant units on how to respond to the growing number of referrals for assessment of patients permanently resident in other countries. The additional guidance is given below:

There is no shortage of serious clinical need for liver transplantation amongst UK resident patients. There is a waiting list for this life-saving procedure and there are insufficient donor livers to cover all patients on the waiting list.

However, the UK must fulfil its legal and treaty obligations to consider offering NHS treatment to patients referred from other member states in the European Economic Area or those referred under reciprocal health agreements. The countries covered are those listed in the 1996 Directions.

The decision as to whether to accept particular referrals from outside the UK is a matter of clinical policy and transplant services will wish to bear the following points in mind:

1. Each of the UK units has a duty to accept all reasonable referrals.
2. In referrals from outside a catchment area, the question should be raised as to whether a patient has been referred from another transplant unit and if not what the grounds are for by-passing their 'local' unit.
3. Quality of care may be compromised in patients travelling long distances for treatment because of the reduced opportunity for the full range of pre-treatment assessment and in the rigour of longer term post-operative follow-up.
4. It may be difficult to ensure the quality of subsequent support in primary care which is an integral part of liver care for UK-based patients with right of access to the NHS.

Given the problems of monitoring high standards in all aspects of care of such patients, liver transplant services should give the most careful consideration to accepting referrals from overseas.

Dr Anne Mackie
Medical Secretary,
National Specialist Commissioning Advisory Group

Transplant Statistics

1 January 2000 to
31 March 2000

Active = Active patients
Sus = Patients temporarily suspended

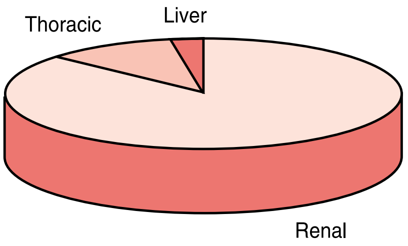
These statistics are provisional and subject to some modification (mainly due to belated notifications). Comparisons are given with activity during the same period (January to March) in 1999. Percentage changes are given when the activity rate is at least 10.

The number of donors reported in 2000 was 213, compared with 189 in 1999.

National Transplant Waiting List at 31 March 2000

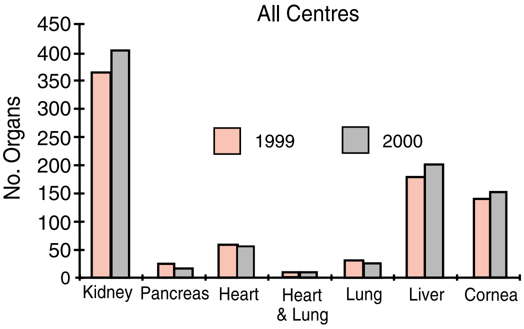
	UK			Republic of Ireland			All Centres
Organ	**Active**	**Sus**	**Total**	**Active**	**Sus**	**Total**	**Total**
Kidney	4730	1105	5835	0	143	143 *	5978
Kidney & Pancreas	56	17	73	0	12	12 *	85
Pancreas	3	6	9	0	2	2 *	11
Heart	180	22	202	22	0	22	224
Heart & Lung	99	6	105	2	0	2	107
Lung	174	10	184	0	0	0	184
Liver	112	7	119	9	0	9	128
Total Waiting	**5354**	**1173**	**6527**	**33**	**157**	**190**	**6717**

* Republic of Ireland operates its own Kidney allocation scheme



Cadaveric solid organ donors reported to UKTSSA classified by organs donated

	UK			Republic of Ireland		
Organ	**1999**	**2000**	**%change**	**1999**	**2000**	**%change**
Kidney	323	374	16	42	28	-33
Pancreas	23	16	-30	2	0	-
Heart	55	51	-7	5	7	-
Heart & Lung	9	8	-	0	0	-
Lung	32	23	-28	0	3	-
Liver	160	182	13	19	17	-10
Total Organs	**602**	**654**	**9**	**68**	**55**	**-19**
Total Donors	**168**	**197**	**-2**	**21**	**16**	**-24**
Cornea	130	149	15	8	0	-



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

	UK			Republic of Ireland			Total		
Organ	**1999**	**2000**	**%change**	**1999**	**2000**	**%change**	**1999**	**2000**	**%change**
Cadaveric Kidney	306	352	15	35	30	-14	341	382	12
Live Kidney	47	80	70	0	0	-	47	80	70
Kidney & Pancreas	8	2	-	1	0	-	9	2	-
Pancreas	1	1	-	0	0	-	1	1	-
Cadaveric Heart	57	53	-7	1	3	-	58	56	-3
Domino Heart	5	5	-	0	0	-	5	5	-
Heart & Lung	10	7	-	0	0	-	10	7	-
Lung	28	22	-21	0	0	-	28	22	-21
Live Lung	2	0	-	0	0	-	2	0	-
Liver / Liver Lobe	156	170	9	8	9	-	164	179	9
Live Liver / Liver Lobe	5	3	-	0	0	-	5	3	-
Total Solid Organ Txs	**625**	**695**	**11**	**45**	**42**	**-7**	**670**	**737**	**10**
Cadaveric Cornea	637	586	-8	25	10	-60	662	596	-10
Live Cornea	0	0	-	0	0	-	0	0	-
Total Transplants	**1262**	**1281**	**2**	**70**	**52**	**-26**	**1332**	**1333**	**0**

CONFERENCE DIARY

2000

NATCO 25th Annual Meeting

5-9 August, Hilton in the Walt Disney World Resort, Orlando, Florida

Information: NATCO

Tel: +1 913 492 3600

First meeting of the International Paediatric Transplant Association

23-25 August, Venice, Italy

Information: Progress Promozione Congressi, Via G. Trevis, 88 – 00147 Rome, Italy

Tel: +39 065 160 0647/48
Fax: +39 065 160 0131
E-mail: progress@progress-congressi.com

XVIII International Congress of the Transplantation Society, Transplantation in the New Millennium

27 August – 1 September, Rome, Italy

Information: Anita Belfiori, Congress Secretariat Tx 2000, Via Proba Petronia 3, 00136 Roma, Italy

Tel: +39 063 972 7707
Fax: +39 063 973 3595
E-mail: a.belfiori@triumphpr.it
Website: www.tx2000roma.it

The British Society for Histocompatibility & Immunogenetics BSHI 2000

11-13 September, Manchester, UK

Information: Kay Poulton, Transplantation Laboratory, Manchester Royal Infirmary, Oxford Road, Manchester M13 9WL

Tel: 0161 276 6667
Fax: 0161 276 6148
E-mail: BSHI2000@man.ac.uk
or, for specific queries: Kpoulton@central.cmht.nwest.nhs.uk

Further details and abstract forms can be downloaded directly from the **Website: http://www.arc.man.ac.uk/BSHI2000.html**

The International Conference of the Royal Statistical Society 2000

11 – 15 September, University of Reading

Information: Lynne Rogers, RSS 2000, Department of Applied Statistics, The University of Reading, PO Box 240, Earley Gate, Reading RG6 6FN

E-mail: rss2000@reading.ac.uk
Website: http://www.rdg.ac.uk/rss2000/

3rd European Day for Organ Donation and Transplantation

23 September, Lisboa, Portugal

Information: Secretariado do 3º Dia Europeu para a Doação de Órgãos e Transplantação.

Novartis Farma, Apartado 153, 2726 Mem Martins Codex, Portugal

Tel: + 351 21 7925595
Fax: + 351 21 9204862
e-mail: Paula.Albuquerque@pharma.novartis.com

2nd Slovenian Congress of Nephrology with International Participation on the Occasion of the 30th Anniversary of Dialysis and Renal Transplantation in Slovenia

27-30 September, Ljubljana, Slovenia

Information: Secretarial Office: Mida Kandus, University Medical Center, Department of Nephrology, Zalo_ka 7, 1000 Ljubljana, Slovenia

Tel: +386 71 324 973
Fax: +386 61 13 22 077

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

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: +351 14 406 200
Fax: +351 14 406 209

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United Kingdom
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