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NHS

UK Transplant

The newsletter for everyone involved in organ transplantation and donation
Issue 54 Spring 2005

In this issue: Spring TV and radio campaign. National research into attitudes to organ donation in the NHS. Approaching families training for transplant co-ordinators. Giving blood – an outline of the National Blood Service. Learning from living kidney transplantation in the USA. Tribute to Mollie McGeown. Small bowel transplantation in the UK. The patients' forum debates living donation. Research projects into corneal transplantation. Appointment with Murat Akyol.



There is continuing progress on a number of fronts. Firstly the Human Tissue Act for England, Wales and Northern Ireland has received royal assent and the majority of its provisions will be effective from April 2006.



The Act establishes the Human Tissue Authority (HTA) as the regulatory body responsible for giving advice and guidance in relation to the Act and it will be established later this year.

One of the statutory functions of the HTA is to issue Codes of Practice. The two codes of particular relevance to organ donation for transplantation are the Code on Transplantation and the Code on Communication, Consultation and Consent.

These draft codes, which will address high-level principles, are currently being written by working groups. Phil Dyer, President of the British Transplantation Society, Keith Rigg, Transplant Surgeon Nottingham, and myself are members of the transplantation group. All the codes will be subject to wide consultation during the summer before they are submitted to Parliament for approval in the autumn/winter.

This is an exciting time for transplantation as the legislation extends the opportunity for live donation (paired and stranger donation) and permits the preservation of organs whilst consent or non-consent is being established.

Secondly, public support for organ donation seems stronger than ever. There are now over 12 million people who have registered their wish to donate on the NHS Organ Donor Register – 0.9 million more than we had at the end of March 2004.

We also know that in the quarter ending 31 December 2004, 24% of all cornea donors and 18% of all solid organ donors were found to have registered their wishes on the ODR. Congratulations are due to all those involved in campaigning tirelessly, locally and nationally, to raise public awareness – it's obviously working.

Thirdly, arrangements are progressing well for the establishment of NHS Blood and Transplant in October 2005. In early February advertisements were placed in a number of papers/journals including the British Medical Journal and the Health Service Journal for a Chairman and six non-executive directors. We anticipate that the appointments will be made during March/April.

UKT and NBA Directors held a very successful joint working day recently during which we highlighted the strengths, overlaps and opportunities for synergy within each component of the new organisation. We also agreed an action plan for joint work that needed to be completed at an early stage to ensure a smooth transition into NHS Blood and Transplant.

Both organisations and our respective Department of Health sponsors are committed to establishing a stakeholder group to advise the "designate" authority on the appropriateness of proposed arrangements. In addition there is ongoing consultation with staff via their trade unions.

All of which bodes well for the future support and development of transplantation services.

Sue Sutherland
Chief Executive
UK Transplant

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*Front cover picture:
New TV fillers on organ
donation out in March.
See News opposite*

VOICE RECORDER

TELEPHONE CALLS TO THE
UK TRANSPLANT DUTY OFFICE

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

UK Transplant Emergency Contact Telephone Number

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

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

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Organ Donor Line 0845 60 60 400 www.uktransplant.org.uk

Massive media blitz



Donor families and transplant recipients are taking the lead roles in a massive media blitz to raise awareness of organ donation and transplantation.

The new campaign, which was launched on 28 February, runs across TV, radio, on-line, magazines and local and national press.

Radio advertisements starring transplant recipients talking about how a transplant has transformed their lives and expressing their gratitude to their donor, are being broadcast on 66 commercial stations across England, Wales and Northern Ireland, reaching a potential 20 million listeners.

The adverts, which will run until 20 March, aim to make people feel positive about organ donation and encourage more people to add their names to the NHS Organ Donor Register.

The radio campaign is being supported by on-line advertising aimed at internet users across a range of websites including AOL, MSN UK and Wanadoo. Space has also been bought on popular news and music sites as well as websites visited by high numbers of black and Asian internet users.



The first five months of the 1 million anniversary challenge has seen nearly 500,000 people add their names to the NHS Organ Donor Register.



One of the TV fillers features Junior Joseph (left), who became a donor, alongside footballer Ledley King.

Five new TV fillers* are also being launched. Two of the fillers feature donor families talking about their loved one and why they are so proud that they followed their relative's wishes and agreed to donation. In one of these fillers football fans will be able to spot brief appearances by England players Ashley Cole and Ledley King.

Two of the fillers feature "vox pops" with members of the public talking about organ donation and why they would be willing to help someone else to live after their death. The fifth uses a game of frisbee to illustrate the amazing impact that one donor can have on many people.

The campaign, which is costing in excess of £500,000, is being supported by public relations activity to encourage the national and local press to cover the launch of the advertising campaign and carry interviews with the donor and recipient families taking part in the adverts.

Angie Burton, UKT's Marketing and Campaigns Manager, said: "This is the biggest advertising campaign UKT has ever done to promote organ donation and we'd like to thank the donor families and recipients who have been

prepared to talk about their experience to help make it a reality.

"We know that millions of people in the UK support organ donation but have never got around to recording their wishes on the NHS Organ Donor Register. We hope this campaign will encourage people to put that goodwill into practice and encourage families faced with the tragic death of someone they love to say "yes" to donation.

"It will give an enormous boost to our aim to add one million more names to the register during its 10th anniversary year."

Public opinion research will be carried out before and after the radio campaign to evaluate the effectiveness of the advertisements and track any changes in attitudes towards organ donation and transplantation.

If you want to see / hear the adverts visit www.uktransplant.org.uk and follow directions from the homepage.

* TV fillers are public information films which are shown free of charge as part of the broadcaster's public service commitment. They are used to "fill" spare or unsold advertising space, which means you're more likely to spot them in the afternoon or early hours of the morning rather than on primetime TV.

New neuro pilot

Two experienced transplant co-ordinators are in post within two neuro units at the Royal London Hospital at Whitechapel and at The University College Hospitals London NHS Foundation Trust.

This is an exciting new pilot project, which began in the autumn, and is being funded for two years by UKT. The transplant co-ordinators are working closely with their colleagues in the units to ensure that all families are offered the option of organ donation.

Kate Torrens began working at the Royal London Hospital in September 2004. She said: "This is a very busy unit because it's a trauma unit and a massive referral centre. I've had amazing support from the consultants and staff here.

"I've been able to see how donation impacts on ICU staff and my role enables me to gain consistent access to information.

"The main difference for me is that, here, I'm an insider on the ICU and the staff feel like they have more ownership over the organ donation process."

There will be ongoing evaluation of the project by UKT.

European partnership working

UK Transplant is taking a leading role in two major projects looking at a wide range of organ donation and transplantation issues in various European countries. The projects are funded by the European Commission.

The ALLIANCE-O project will look at ways of increasing the number of available donor organs, the efficiency and equity of organ allocation procedures and increasing the safety and quality of organ transplantation.

It is recognised that UK Transplant is at the forefront in the evaluation of organ allocation schemes and the continuous monitoring of the performance of different transplant centres.

Involvement in this project will enable other countries to implement these procedures.

The result will be a harmonisation of best practice in organ transplantation and research activity.

The other project, DOPKI (Improving the Knowledge and Practices in Organ Donation), will study ways to improve organ donation rates and the factors affecting whether someone becomes a donor.

UK Transplant will bring statistical expertise to this project as well as experience gained from the Potential Donor Audit to identify the true potential for organ donation in this country.

As each of these projects develops UKT will seek to involve clinicians in the work. UKT will benefit from the sharing of ideas and expertise in a number of areas, and from links that will be forged with Eurodonor.

Valentine's message

Millions of Co-op pharmacy customers were given the opportunity to send free Valentine's cards to their loved ones this year and save someone's life by registering as an organ donor at the same time.

Health Minister, Rosie Winterton, helped launch the campaign in Southampton, one of more than 350 Co-operative Group pharmacies across the UK stocking the special cards.

The card asks people to "give someone the ultimate gift this Valentine's Day – the gift of life." The card includes all the information needed to join the NHS Organ Donor Register.

Sue Sutherland, UKT chief executive, said: "Co-op pharmacies are to be congratulated for encouraging their customers to both think about organ donation and take action to register their wishes. This will inevitably lead to the opportunity to save more lives."



Liz Colling (left) of Co-operative Group Pharmacy, Debra Colfer (centre) a patient who has been waiting nine years for a suitable donor kidney, and Rosie Winterton (right) Health Minister at the launch.

Twice as many NHS staff signed up to ODR

A national survey of health care professionals has shown strong support for transplantation.

A total of 350 NHS staff were questioned in the survey conducted by UK Transplant.

More than nine out of ten (94%) said they supported transplants because they save and dramatically transform the lives of recipients.

The number of staff who had put their names on the NHS Organ Donor Register (38%) was almost double the national rate of registrations among the general public.

Registrations were highest among transplant staff (53%) and intensive care teams (49%) followed by GPs (44%) hospital nurses (36%) hospital doctors (30%) and senior managers (20%).

The reason most frequently given by NHS staff for not joining the ODR was that they had "not got around to it" although one in five assumed there was no need to register because they carried a donor card.

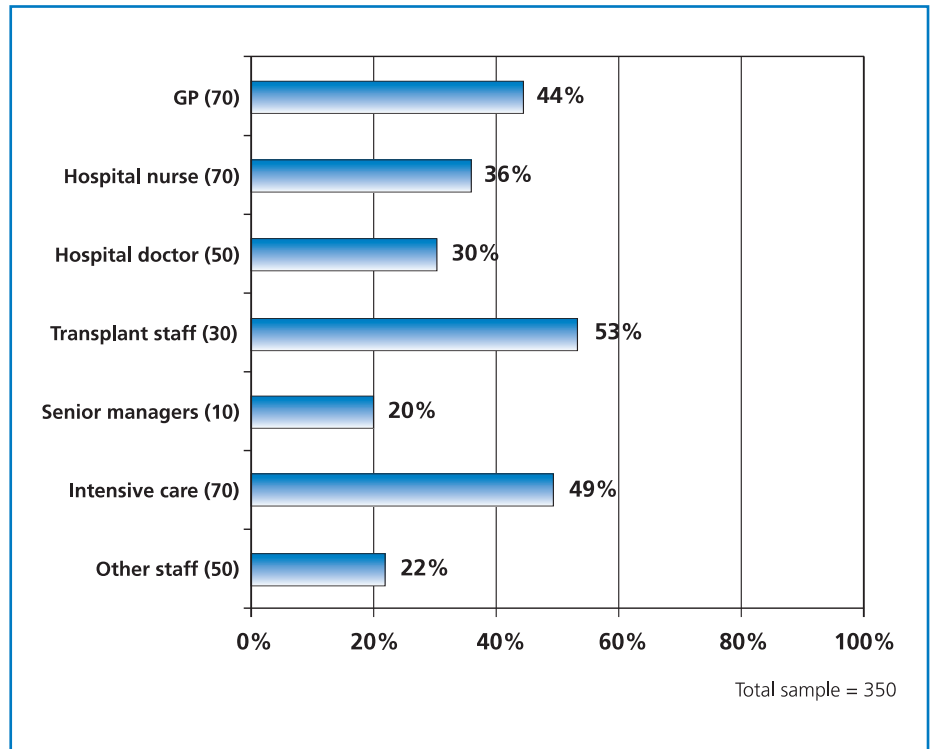
Sue Sutherland, chief executive of UK Transplant, said: "I am delighted at the high awareness of transplant issues among health care professionals and the recognition of the benefits for recipients.

"I am also pleased that registrations on the ODR among health staff are double the national average – and even higher among front line staff including GPs."

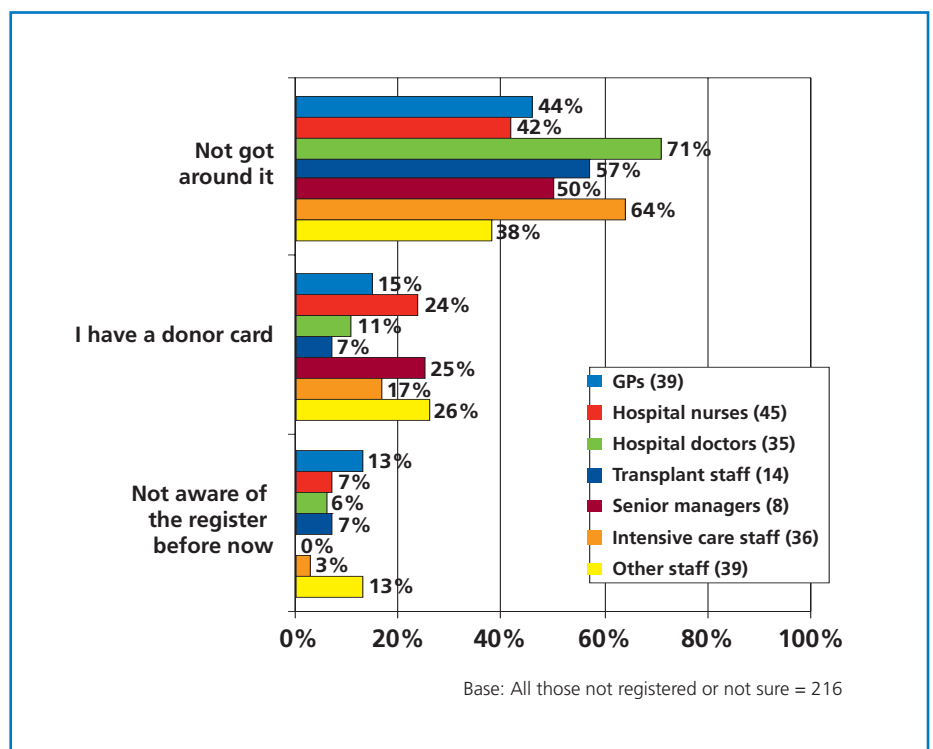
The survey did highlight some confusion over whether people carrying donor cards needed to add their names to the ODR.

And nearly half of those questioned (43%) felt strongly that where someone had made it clear they wanted to donate their organs, either by having a donor card or registering, it should not be necessary to get permission from the next of kin, with only 13% strongly disagreeing.

Comparing groups of staff registered on the NHS Organ Donor Register



Reasons given for not being registered on the NHS Organ Donor Register



New donor datasets pilot – thank you

The need to review data collection was identified by the UKT advisory groups and the Royal College of Surgeons (RCS). As a result the data requirements are changing to cater for auditing transplantation through the next decade and beyond and to enable more detailed analyses of outcomes. The changes will affect all of the data forms for each organ type to a greater or lesser extent.

The first stage was to revise the donor data collection forms and the pilot of the revised core donor and organ specific donor forms has just finished. UK Transplant wishes to thank all those who participated for their involvement in completing and using the pilot forms. At what is usually a very busy time, the pilot made

additional demands, but it was important that the forms were used in earnest.

At UKT we are now beginning the task of reviewing the feedback from the pilot. This will help determine what changes are needed to the revised donor forms and accompanying documentation. We shall then be able to assess the full extent of the changes required to UKT's systems in order to replace the current forms with the new ones.

For general enquiries about the pilot of the revised donor forms please contact Frances Seeney on 0117 975 7539 or email: Frances.Seeney@uktransplant.nhs.uk

Do it now!

In January transplant staff urged the public to sign up to the NHS Organ Donor Register through the "Do It Now!" campaign.

The campaign gave NHS staff the chance to do something they had always wanted to try and, in doing this, encouraging people to turn their own good intentions into action.

Penny Hallett, Director of Communications for UK Transplant said: "Many of us start the new year full of good intentions of things we want to do. All too often these good intentions go to the bottom of the 'to do list', and we don't take action. Our message is simple – if you want to do something positive, 'Do It Now!'"

From Belfast to Bristol, staff fulfilled lifelong dreams such as rally driving, being an haute cuisine chef for the day, driving a Ferrari, riding with the crew of a fire engine and 4x4 off-roading. But the message of the campaign was a serious one, as Tina Broadly, from Cambridge's Addenbrooke's Hospital explained: "Riding with the crew of a fire engine and hearing the sound of the sirens ringing in my ears is something I've always wanted to do –



Above: Tina Broadly fulfilled a lifelong ambition by joining the Cambridge Fire Crew and urged people to join the NHS Organ Donor Register.

but there's a really serious ambition behind this campaign. We urgently need more people to think about organ donation, talk to their families and join the NHS Organ Donor Register. We know there is a huge amount of goodwill out there, we just need people to turn their good intentions into action, and we ask them to please 'Do It Now!'"



Belfast Transplant Co-ordinator, Heather Savage, with Kris Meeke, rally champion.

Credit: Cambridge Evening News



Kidney transplant recipient, Dave Clark, turned the tables on the Prime Minister Tony Blair during a visit to Manchester. Dave was presented with an award for his work in the community, but managed to give Mr Blair an ODR registration form in return. A former professional rugby player, Dave is a member of the Great Britain Transplant Games team and is hoping to compete in the World Transplant Games in Canada later this year.

Transplant Torch relay

Volunteers are needed on the donor bus to help at the following stopping off points:

Tuesday 16 August - Norwich
Wednesday 17 August - Peterborough
Thursday 18 August - Lincoln
Friday 19 August - Grimsby
Saturday 20 August - Hull
Sunday 21 August - York
Monday 22 August - Wakefield
Tuesday 23 August - Sheffield
Wednesday 24 August - Chesterfield
Thursday 25 August - Loughborough
Friday 26 August - Nottingham
Saturday 27 August - Leicester
Sunday 28 August - Loughborough University

If you can help contact:

David Nix of the Donor Family Network
 Tel: 07799 346128

Transplant Week and Donor Days

This year, National Transplant Week runs from Sunday 3 July – Sunday 10 July. And there will be two donor days: National Donor Day North will be held in Newcastle on 25 May 2005; and National Donor Day South will be held in Cambridge on the 14th October 2005.

For more information about Transplant Week or Donor Days contact:

Sue Johnstone at Transplants in Mind
 Tel: 0117 931 4638/07702 853 189
 Email: sue@transplantsinmind.fsnet.co.uk

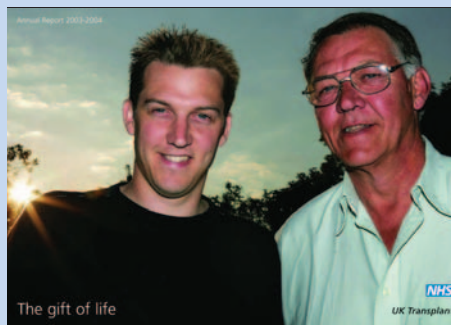
MBE honour for David

David Nix, founder of the Donor Family Network, recently visited Buckingham Palace to receive an MBE. David, whose own daughter became a multi-tissue donor in 1996, works tirelessly to help support other donor families, and to promote awareness of organ donation, by touring the country with his donor bus.

He hopes "that the award will further help to raise the profile of the need to join the Organ Donor Register" and that, whilst he is very pleased to be awarded the MBE, he also acknowledges "thanks to the many

other people behind the scenes, whose help and support has been invaluable in raising awareness".

David also adds that he feels that his daughter would be pleased that he has received an award that celebrates his efforts to help others, and hopes to ensure that the award is used to maximum effect to promote awareness through the Donor Family Network. David is looking forward to touring the donor bus during the Transplant Torch relay, which begins at the venue of last year's Transplant Games and carries on to this year's venue in Loughborough.



UK Transplant was delighted to be a runner-up in the NHS annual report awards, in the category of national health body. Janice Tye, UKT's Graphic Designer, and Clare Hanson-Kahn, Publications Manager, attended the awards ceremony and were pleased to be able to bring back a plaque!

Small bowel transplantation – dawn of a new era

Birmingham is the only centre in the UK which carries out small bowel transplantation in children. It is a relatively uncommon procedure with just 26 transplants carried out in 15 years. This article has been written by members of the liver unit at Birmingham Children's Hospital and the hepatobiliary unit at Queen Elizabeth Hospital.

Small bowel transplantation is a life-saving procedure for some children with intestinal failure. Although many children with intestinal failure can be supported on home parenteral (or intravenous) nutrition, about 20% will develop life-threatening complications including recurrent line infections, loss of central venous access and progressive liver disease.

An alternative treatment for children with complications of chronic intestinal failure is intestinal transplantation. Worldwide, approximately 1,000 intestinal transplants have been performed since 1 April 1985 and at present there are 61 intestinal transplant programmes in 19 countries.

Depending on the severity of the liver disease, small bowel transplantation can be performed involving the small bowel alone or with other organs: small bowel alone - mild liver disease and / or impaired venous access liver and small bowel - end stage liver disease multivisceral transplant (liver, small bowel, duodenum, pancreas etc).

As with other types of organ transplant, there has been a steep learning curve; with worldwide figures showing about 20% long-term survival of patients transplanted in the 1980s and early 1990s.

In the 1990s, with increasing experience in intestinal transplantation and improved immunosuppressive protocols incorporating tacrolimus, five-year survival of 50% was reported. However, with the advent of newer immunosuppressive regimens and the use of newer monoclonal antibodies such as basilixumab, daclizumab and antithymocyte globulin, one-year survival of 80% has been reported from the USA.

Major obstacles to the development of safe and reliable intestinal transplantation are largely those of late referral, availability of size-matched organs, opportunistic infection and graft rejection.

Children recommended for liver and small bowel transplants can wait for size-matched organs for 6-12 months and, tragically, some children can deteriorate and die on the waiting list. In order to reduce the mortality on the waiting list, surgeons have pioneered the technique of graft reduction, taking the smaller left lobe of a liver from an adult along with the small bowel for transplantation into a child.



Six-year-old Aaron Gray, from Peebles, received a liver and small bowel transplant when he was just three years old and has undergone two heart operations. In October he was one of ten transplant recipients to meet the Prime Minister to celebrate the 10th anniversary of the NHS Organ Donor Register.

This practice alongside effective immunosuppressive regimens in preventing rejection and the use of better monitoring techniques in detecting opportunistic infections (CMV and glandular fever virus) have contributed to a significant reduction in morbidity and mortality.

With improved long-term survival there has recently been a greater focus on the quality of life of intestinal transplant recipients and a study in the USA was conducted in 10 to 16-year-old small bowel transplant recipients.

The study showed that the recipients rated their quality of life as equivalent to healthy children of the same age, although their parents remained more anxious than the parents of healthy children. Most of the children attended school and led a normal life, similar to other children of the same age.

The UK experience

Over the past 15 years, 153 children have been assessed for small bowel transplantation at Birmingham Children's Hospital. Of these children, 54 were recommended for transplant following a multidisciplinary assessment.

Four children are currently still on the waiting list. Fourteen have died on the waiting list over the past 12 years because of sepsis and end stage liver disease (mostly during the first phase of the programme at Birmingham before the technique of graft reduction was developed).

Over the past 15 years 26 children have undergone small bowel transplantation and, of these, 17 children were

Continued from page 8

discharged home, free from parenteral nutrition. Of these 17 children, there are now 12 surviving weaned from parenteral nutrition onto oral feeds.

Dr Girish Gupte, Consultant Paediatric Hepatologist at Birmingham Children's Hospital said: "With the advances in immunosuppression and increasing experience worldwide, survival following intestinal transplantation is improving and recipients are enjoying a good quality of life.

"Intestinal transplantation is now an established option for those who cannot be managed successfully on total

parenteral nutrition. In such cases, early referral to an intestinal transplant centre is strongly recommended."

For more information about the programme at Birmingham Children's Hospital, contact Girish Gupte, email: girishgupte@hotmail.com

For more information on small bowel transplantation see www.intestinaltransplant.org

Contributors: Gupte G, Beath S, Sharif K, Millar A, Kelly D: Liver Unit, Birmingham Children's Hospital; Mayer D, Mirza D: Hepatobiliary Unit, Queen Elizabeth Hospital, Birmingham

Corneal transplantation projects

Although recently referred to in the American Journal of Transplantation as the "forgotten graft", corneal transplantation is, in fact, the most commonly performed transplant in the UK, with 2,365 transplants carried out in the last financial year. Mark Jones, UKT's Ocular Tissue Data Series Specialist, outlines some recent research projects.

UKT's Statistics and Audit Directorate has been working with students from the University of Reading and the University of the West of England, who have written MSc dissertations on a range of corneal transplantation topics.

One study investigated the factors influencing visual acuity score improvements following corneal grafts. These scores are used to determine whether a patient's vision has improved following a corneal graft. This project considered patients who received a penetrating graft for Keratoconus, Fuchs' dystrophy or Pseudophakic Corneal Oedema, three of the commonest indications for corneal grafts in the UK.

At the one-year follow-up, 85% of patients with a functioning graft showed improvements in visual acuity,

with only 6% having poorer acuity and 9% having no change in acuity. Pre-operative acuity, indication for graft, whether the recipient had any pre-operative conditions that may have affected visual acuity, recipient age and the total number of grafts performed by the surgeon, were all found to influence the level of improvement in acuity.

Research was also undertaken on repeated visual acuity scores. These scores are reported to UK Transplant pre-operatively and at one, two and five years following the transplant.

This enables us to look at the change in visual acuity over time. The research showed that change in visual acuity was dependent on recipient age, graft survival time, HLA matching, number of previous grafts, total number of grafts performed by the surgeon and whether the recipient had any pre-operative conditions.

A number of patients receive a corneal transplant in one eye, followed by a transplant in the second eye some time later. The effect of the time between transplants was explored in a third study. The success of the first graft was shown to increase with the length of time between the two transplants.

In addition, if the first graft fails this tends to increase the risk of failure for the second graft.

Very often, patients have more than one graft in one eye. Outcomes of these grafts were expected to correlate to show that a relatively short graft survival time for the first graft would lead to the second or subsequent graft also having a relatively short life time. However, the research, somewhat surprisingly, found that this correlation was actually quite small.

Other cornea topics that are currently being investigated include looking at the factors influencing graft survival for patients suffering Keratoconus and, in particular, whether there is a difference in graft survival between the two main procedures used for this indication.

Another area of research, being carried out with Bristol Eye Hospital, will investigate whether graft survival is better if antiviral medications are administered post-operatively for patients who received a corneal graft due to viral infection.

For more information on any of these studies contact Mark Jones on: mark.jones@uktransplant.nhs.uk

Giving blood saves lives

On the 1 October 2005 UK Transplant merges with the National Blood Service (NBS) to become a new authority, NHS Blood and Transplant. Here, Jude Pamington, NBS regional communications manager gives some background to the role of the NBS.

With over 6,000 employees and fifteen blood centres, the National Blood Service is a large and eclectic organisation. It is an integral part of the NHS; supplying blood, blood products and tissues to 310 hospitals across England and North Wales. The NBS is part of the National Blood Authority (NBA), along with the Bio Products Laboratory (BPL) at Elstree.

Blood is a versatile product that can be used to stem blood loss during or after an operation, provide essential support during cancer treatments such as chemotherapy and give newborn babies a fighting chance. The demand for blood never stops and the NBS must collect 9,000 donations every day to keep stocks buoyant. It relies on voluntary non-remunerated donors, who give because they want to help save lives. Last year, over two million donations of blood were given by more than 1.3 million donors. Just 6% of the eligible population currently give blood, so one of the Service's biggest challenges is to ensure that regular donors keep giving blood and raise awareness amongst those who can, but don't.

Blood is rarely used as a whole product. It is usually separated into three components: red cells, plasma and platelets, each of which has its own life-saving qualities.

Patient safety is paramount so every unit is tested for a range of blood-borne diseases such as HIV and hepatitis. All testing and processing must meet Good Manufacturing Practice and EU Blood Directive standards and centres are regularly inspected by the Medicines and Healthcare products Regulatory Agency.

Red cells last for 35 days after donation, while platelets last just five. It is therefore vital that stocks are managed wisely and that blood is used appropriately. The NBS works in close partnership with hospitals, NHS Trusts and the Department of Health to promote such appropriate use and this action has resulted in a predicted 6% reduction in the demand for red cells in 2004/05.

The NBS also provides a complete range of diagnostic services to hospitals including tissue typing for approximately 40% of solid organ donations, transfusion microbiology and scientific teaching and training in transfusion medicine. It also carries out a range of antenatal services for around a third of NHS facilities.

In addition to collecting, processing, testing and issuing blood, the NBS also has a world-class team of scientists and medics who are driving forward international agendas on research and development. Current areas of research include tissue and cellular engineering, protein engineering and blood and tissue safety.

Tissue services is a growing field for the NBS, which is now the largest multi-tissue banking organisation in the UK. The Service runs a tissue donation programme, collecting bone, heart valves, tendons, skin and managing referrals for corneas. In 2003/04, around 4,800 tissue grafts were issued to hospitals (364 tissue retrievals from cadaveric donors and 4,184 from surgical donors).

In addition, the NBS runs and promotes the British Bone Marrow Register (BBMR), and runs the London Cord Blood Bank. It also collects, processes and cryopreserves stem cells – another rapidly developing field of research.

The NBS is joined under the NBA umbrella by BPL, which employs 600 staff. BPL develops and manufactures a range of therapeutic products from plasma, which is imported from the US. Plasma is a rich source of proteins; proteins that are used to produce coagulation factors (such as factor VIII for haemophiliacs), immunoglobulins and albumins. BPL is an essential part of the NBA and, along with the NBS, contributes to saving and improving the lives of thousands of sick and injured patients each year.



The NBS must collect 9,000 blood donations every day.

Debating living donation

The patients' forum meets twice a year to advise UKT and feedback issues relevant to organ donation from a patient's perspective. Each of the members of the forum brings their own personal experience of transplantation – as recipients, as donor families and as patients on the transplant list. At the last meeting, the patients' forum discussed living organ donation and, here, Lynne Burton reveals some of the discussion that went on behind the general consensus reported.

As members of the patients' forum we bring to the table a wealth of personal experiences and emotions. Our contributions are not based on scientific reasoning and deep medical knowledge – but the valuable experiences of ordinary people.

In our last meeting we looked at three different scenarios – related donation, paired donation and altruistic “stranger” donation.

Initially we wanted to spend very little time on related donation as this is routinely done and none of us were against it. However, there were concerns about the knowledge we had of the effects on the donor. Not just the long-term medical implications but also the altered dynamics of the family group and specifically the donor/recipient relationship.

We know that this type of information is being collected and research is ongoing and this reassured us that the major concerns we had as a group were already starting to be addressed by the health professionals in transplantation.

Next we looked at paired donation, which in principle seems like a very good idea but then we started thinking about the logistics. Should the transplants be done almost simultaneously – as if one donor pulls out after their recipient had received their organ where does this leave the other recipient?

Should we be looking at doing both operations in the same hospital – while this would result in the shortest “down time” there would then be the problems of operating theatre space. Having both donors and recipients in the same hospital would also inevitably mean they have more knowledge about each other. How would you feel as a donor if your relation died and the recipient of your organ did really well?

We agreed that, in theory, with paired donation that the outcome shouldn't matter, but again we have no knowledge of that and the places in the world where paired donation already takes place have different cultures.

We were also worried about how you would match these pairs – you could start to see eBay organising pairs over the



Debates within the forum are lively and challenging.

internet. I think this way of pairing should definitely not be allowed to happen, as it represents the thin end of the wedge and would be the start of selling organs.

As a group we couldn't decide what information should be available to each pair in terms of outcome for the other pair. Some of us felt that no information should be available, and others that they should be allowed the same information that you are allowed post-cadaveric donation.

Lastly we discussed altruistic or “stranger” donation. Some of us couldn't actually believe that this could happen, as anyone willing to say “hey, I've got a spare kidney do you want one?” must be mad. When we learned about the trials that were going on in the USA and that, with strict controls, they had done 25 transplants in five years, we were amazed. As a group we are, of course, totally in favour of anything that increases the number of organs available.

It would be vital to make sure that no money or other incentives were given. Not only does there need to be good screening to make sure no people without truly altruistic reasons can be allowed to become donors: it is imperative that potential donors have proper counselling before and after donation.

Personally, I am still not convinced that there can be truly altruistic donation as, surely, the donor must want to get something out of it. Maybe they would do it for the attention?

After all the intricate debate, the group agreed with all three ways of living organ donation, but felt that there needs to be a more comprehensive support system for the donors, post-transplant. The donor is, after all, just as important as the recipient, and we should not forget them once they have donated.

Approaching families training

Throughout last year, UK Transplant organised training for all donor transplant co-ordinators to teach them different methods in approaching families for organ donation. This included techniques in how to gently probe families' reactions and thoughts.

The training was provided by Margaret Verble and Judy Worth, who run in-house courses in the USA on how to approach families and make the request for organ donation. They have been teaching a collaborative requesting model for the last 25 years in the USA and Canada, which uses a joint approach from the transplant co-ordinator and the health care professionals who have been caring for the patient.

Sue Falvey, UKT's Director of Donor Care and Co-ordination, said: "The training provided an invaluable experience that will influence donor transplant co-ordinators' practice in the future and which we hope will help increase the consent rate, which in the UK is 58% of families."

The US experience

Margaret Verble, one of the US trainers, said: "In our hospitals where best practices are applied, consent rates for white people run at about 90%. In hospitals where those practices aren't applied, often the consent rates are 20-25%. With minorities the consent rates are always lower."

Research carried out by Margaret Verble in Ohio, Texas and South Carolina, which are very diverse in population and culture, showed a 77.3% consent rate for white people and a 30.3% consent rate for African-Americans.

When asked about the training she had delivered in the UK, Margaret said: "We found training the UK donor transplant co-ordinators a pure pleasure. Not only is the model of requesting we teach very compatible with the values and manners of the UK delegates and the overall programme in the UK, the interpersonal skills level of the donor transplant co-ordinators is, overall, very high.

"In comparison to their counterparts in the US, most of them have been in post longer and have the kind of maturity it takes to help families who are in grief. The one or two places where there are cultural differences between our countries – for instance, in the US we tend to bury the dead more rapidly than in many parts of the UK – we were able, with advanced preparation, to make adjustments in the workshop content to make it culturally appropriate.

"We have high hopes that this training will be helpful to organ donation efforts in the UK, but only time will tell."

Feedback from the Birmingham transplant co-ordinator team

"When we initially saw the programme, our instant response was "Oh no, not role-play!" But it turned out to be not only a fantastic learning opportunity, but also an enormous amount of fun.

During the training we were all given the opportunity to play a co-ordinator who was making an approach for donation to various members of a family with challenging characteristics and misconceptions about organ donation, role-played by our donor co-ordinator colleagues.

Many of the situations were hilarious, as they were totally extreme, but laughter played a huge part in giving us all the confidence we needed to throw ourselves into the role-play. The lessons we learned were valuable not just for co-ordinators new to post, but also those with several years' experience.

Margaret Verble and Judy Worth provided two excellent days of training, providing theoretical, evidence-based

"We have high hopes that this training will be helpful to organ donation efforts in the UK, but only time will tell."

information allowing us to question the way they practise in the USA and how we can best use their experience to suit our needs in the UK.

In particular, it has allowed the team in Birmingham to re-evaluate the way we approach a collaborative request.

For example, it raised the need to identify from the outset clear roles between the donor transplant co-ordinator and the health care professionals who have been caring for the patient, when making the request for donation.

We must remember that we are the experts in the field of organ donation. Donor transplant co-ordinators are up-to-date on all aspects of organ donation and can often reassure families who need further information or do not understand what the process involves.

Some health professionals have perceived the donor transplant co-ordinator presence during an approach for organ donation as coercive. This training has given us all the confidence to reaffirm to referring units that evidence suggests that when a donor transplant co-ordinator is present during a donation approach, the family will have a more positive experience, as the co-ordinator will be there to answer any questions and offer support, whether donation goes ahead or not.

Another topic that was discussed during the training is the need to find out the exact reasons for a family refusing donation. Sometimes by gently enquiring into why they have said "no" for example, "I don't want him to suffer any more", we can correct misconceptions or allay fears, and this may be enough to reassure the family and convert an "unsure" into a "yes".

Although collaborative requesting had already been accepted as a policy and put into place in several referring units in the West Midlands before this training, the team now feel more confident to put the principles into practice.

We will of course monitor our progress and hopefully reduce the family refusal rate into the bargain!

“The training provided an invaluable experience that will influence donor transplant co-ordinators’ practice in the future and we hope will help increase the consent rate.”

Putting it into practice

Just three days after the training, Laura Sedgley, Donor Transplant Co-ordinator at St James’ Hospital in Leeds, had a chance to put her training into practice.

During the training we looked at the theories behind why relatives refuse organ donation, the practice of collaborative requesting and the needs of the family. The actual request for organ donation was broken down into a three-step approach: the death conversation (the subject of death and funeral arrangements), the clean up conversation (checking the relatives’ understanding and correcting any misconceptions) and, finally, the donation conversation.

Just three days later I had my first opportunity to practice what I had learnt. The interview took considerably longer than previous interviews I had conducted, but I felt that I was able to give a lot of information in a way that was much easier to understand, for example using visual aids to explain brain stem death and spinal reflexes.

Six weeks after meeting the family, I visited them at home and they commented that I gave them the answers to questions they had previously felt "silly" asking and that

I was the first person to talk about funeral arrangements, information which they considered vital as they had never had any experience of this.

Certainly, the feedback my colleagues and myself have received from donor families since implementing this new approach has been favourable.

As a team, we are talking to ICU colleagues about this new way of approaching families for organ donation. At a recent study day we facilitated groups of ICU medical and nursing staff performing role-play using this new approach. The reaction has been positive and certainly some colleagues are expressing interest in a collaborative approach.

Pilot workshops with consultants

To follow on from the transplant co-ordinator training, two pilot workshops are being planned for senior ITU clinicians from West Yorkshire and from London.

Senior doctors will be invited to take part in the training, which will continue to explore the USA’s collaborative model and see how transferable it is to a UK setting.

Living donor kidney transplantation: what can we learn from the USA?



Last year Dr John Scoble, Consultant Nephrologist and Lisa Burnapp, Nurse Consultant for Living Donor Renal Transplantation, from Guy's & St Thomas' Foundation NHS Trust, visited two large transplant centres in the USA to study the differences in approach between USA and UK practice. Here, Lisa Burnapp writes about what they found out.

We visited the University of Minnesota and The Mayo Clinic, hoping to gain new momentum for our own programme by looking at the American experience – where a two-fold increase in living donor kidney transplantation has been achieved during the last decade.

Each centre provided a unique perspective; the University of Minnesota as an historically well-established programme with a progressive increase in living donor activity over time, and The Mayo Clinic with a rapid growth (50 to 200 transplants) within the previous five years.

One of the key differences between UK and US practice is the emphasis on pre-emptive living donor transplantation and promoting this as the best option for patients approaching end stage renal disease. The provision of accurate, realistic information for both donor and recipient at an early stage is central to the success of this approach.

The criteria for acceptance for potential transplant recipients for living donor transplantation is broader than that widely adopted within the UK, offering higher risk patients the benefits of the best option available for transplantation.

Both centres almost exclusively perform laparoscopic donor nephrectomy, which is considered to be the only viable option in a geographically diverse health economy that is driven primarily by patient choice.

If more than one donor is investigated in the course of finding a suitable donor to proceed to donation, funding streams are designed to support the additional costs incurred.

There is no specific legal framework which governs living donation and there are fewer constraints on permissible combinations of donor/recipient pairs in unrelated scenarios which increases the scope of the donor pool.

There are mechanisms in place to support non-directed (altruistic stranger) donation and transplants from blood group (ABO) incompatible donors.

Since our visit, within our own centre, we have put a number of initiatives in place as part of a locally sponsored modernisation initiative.

A DVD/video for potential donors, based upon the American model, has been filmed within the centre. This is being funded collaboratively by the Guy's & St Thomas' Charity and a national joint industry / UKT / Department of Health project and will also be used by the pilots at

Wolverhampton and Preston hospitals, which are funded through the industry project. The DVD will be offered to potential transplant recipients at an early stage in the pre-dialysis setting and made available for donors who express an interest in living donation.

By using a different, but very simple, way of measuring pre-dialysis patients' estimated glomerular filtration rate (eGFR) from their routine blood tests we have been able to improve accuracy of their estimated renal function. This helps us to plan when the best time is for pre-emptive transplantation.

We have also developed the infrastructure to support an ABO incompatible living donor transplant programme, meaning more donors could be considered. Although we have not yet performed one of these transplants we have written to all the patients on the active transplant list to let them know about this development.

In the USA patients with higher risk factors are considered for living donation. This has prompted us to re-examine our recipient acceptance criteria to see whether more patients could benefit from a living donor transplant.

Although only a few centres in the UK currently offer laparoscopic donation, the US experience indicates that there will be an increasing demand for this type of surgery in response to patient choice.

We have a well-established laparoscopic donor programme initiated in 2003, and in 2004 we were able to offer this to almost 50% of all patients undergoing donor nephrectomy with excellent outcomes.

For a full report of the findings, see the UKT website under the how to become a donor section/living kidney donation.

Mollie McGeown – a woman of principled toughness

Professor Mary G (Mollie) McGeown
(1923 – 2004)

Dr James F Douglas, Consultant Nephrologist and Transplant Physician, worked with Professor McGeown for 20 years at the Department of Nephrology and Transplantation, at Belfast City Hospital. This is his tribute to Mollie McGeown.

Mollie McGeown, the architect of Northern Ireland’s dialysis and transplantation service, was best known for the “Belfast Recipe” of immunosuppression, based on low dose steroid, isolation against infection and intensive nursing.

Excellent graft survival, with low mortality, confirmed the clinical value of transplantation at a time (the early 1970s) when some doubted it. Many patients from that era, among the longest surviving recipients in the world, still attend for review.

The daughter of a farming family, Mollie started her career as a clinical scientist, making contributions in the fields of calcium disorders and renal calculi before taking up the challenge of renal failure in 1959.

She faced prejudice as well as daunting clinical problems in the early years, but overcame both with ability and determination. She produced over 350 articles in the course of her career, with books on transplantation and electrolyte disorders, and made influential reports on the epidemiology of renal failure.

Among other distinctions, she was chairman of the UK Transplant Management Committee (UKTS) and president of the Renal Association. She served on the London Renal Services Review and on ULTRA (the Unrelated Live Transplant Regulatory Authority).

She was made CBE in 1985 and Professorial Fellow at Belfast in 1988. In 1998 she was named among the 50 most influential women in NHS history. She continued clinical research to the end of her life.

Mollie’s chief qualities were wide knowledge, shrewd clinical judgement, dedication, administrative ability, reliability, resolution and legendary force of character.

Physically small, she nevertheless exuded authority, always aiming at excellence and also expecting it. Her “combat-readiness” offended some, but Mollie was always receptive to reason.



Her principled toughness gained the respect of both colleagues and patients, which found expression in the Northern Ireland Kidney Research Fund. Set up in 1971, it has raised several million pounds. Mollie returned the regard in full measure and in many ways. One was her long support for the Belfast Transplant Games team. She played a leading part in the Belfast Games of 1998.

Mollie’s medical career co-existed with another as a housewife and mother. Married to Max Freeland, of Queen’s University, she raised a family of five boys for whom she was always on hand to make the evening meal and provide maternal duties.

With Max up to his death in 1982, and later on her own, she presided over a comfortable, efficient, upright and enlightened household, to which she often welcomed colleagues, many from overseas, with whom she delighted to discuss favourite interests such as antiques and local history.

Mollie was a remarkable person who will be long remembered.

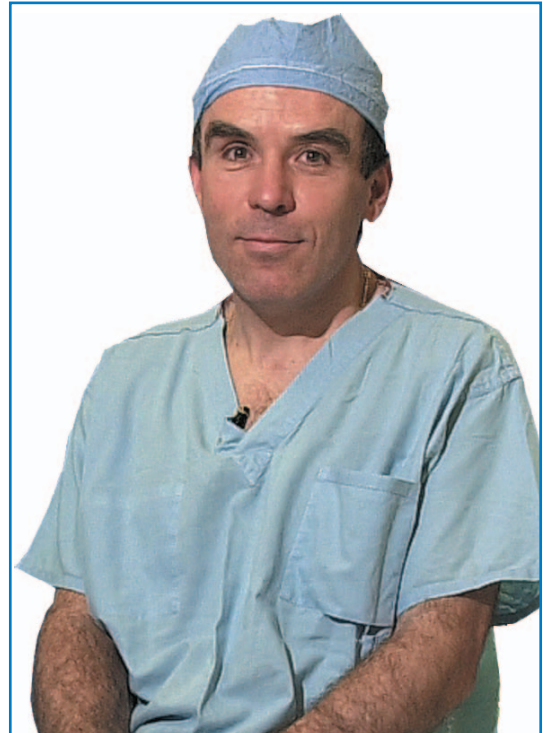
...Murat Akyol

Murat was born and grew up in Ankara, Turkey. He graduated from the University of Ankara, Medical School and undertook basic surgical training for three years at his home University.

In 1984 Murat visited the Transplant Unit and the University Department of Surgery in Glasgow as a British Council Fellow. This project ran into further surgical training and he completed his higher surgical training in Glasgow.

Murat was appointed as a Consultant Surgeon in Renal Transplantation in Glasgow in 1992. He moved to his current post (Consultant Transplant Surgeon – Honorary Clinical Senior Lecturer) at the Royal Infirmary of Edinburgh in 1997, primarily to broaden his practice in organ transplantation to liver and pancreas transplantation as well.

He set up Scotland's first pancreas transplant centre in Edinburgh and this is now one of the largest centres in the UK.



Q What prompted you to specialise in renal transplantation?

A It was simply serendipity. As an impressionable new surgical trainee, one of my most inspiring surgical mentors had renal transplantation as his main interest, which was quite a rare thing in those days. I followed and liked it. I then went on to extend my experience to pancreas and liver transplantation.

Q What else might you have done?

A Ophthalmology.

Q What aspect of your role excites you most?

A One of the best "sights" in surgery, which I still feel excited by every time I see it, is a kidney (or liver or pancreas) transplant perfusing with blood in the operating theatre and producing urine (or bile or pancreatic juice).

Q What aspect do you least enjoy?

A Without doubt the most challenging part of my job and the aspect that I enjoy least is being involved in paediatric cadaveric organ donors.

Q What has been the greatest success in your career?

A I can't immediately single out one; all of my patients who have had successful transplants. If you ask any doctor what's special about medicine, it's the huge amount of satisfaction you get from helping patients. Maybe what's different about transplantation compared to other surgery is that rather than removing things from people, you are adding organs.

Q What one piece of advice would you give to someone new to transplantation?

A Persevere. It is technically demanding and exciting, intellectually very stimulating and ultimately more rewarding than most other surgery.

Q What has been the most radical change since you have been involved with transplantation?

A My introduction to transplantation was in the early 1980s. The success of transplantation has been so phenomenal and it has been achieved in such a short period of time, that transplantation has become a victim of its own success by creating the current

mismatch between demand for transplantation and the number of transplants we can perform.

Q If you were made Secretary of State for Health tomorrow, what would you do?

A Turn the job down or look for the earliest possible opportunity to give it up! Kidney transplantation is hugely cost-effective for the health service compared to dialysis. The one resource we really lack in transplantation is organs, so it's not as simple as putting more money into transplantation.

Q What is your most memorable moment?

A Too many to count. I feel quite passionate about most things I do. Hence on most days in my life something happens that I consider to be my most memorable moment, usually until the following day when I experience something else equally memorable.

Q How do you relax?

A Classical music, opera, tennis and running.

Pancreas Task Force (sub-group of Kidney & Pancreas Advisory Group)

PTF met on 29 October 2004

- Work is underway to secure funding for the extra costs involved in retrieving pancreata for islet transplantation. This would allow further islet transplants to take place in order to provide sufficient evidence for recognition as a clinical specialty.
- Consideration was given to arrangements for pancreas transplant units to advise UK Transplant of the type of offer they wish to consider when registering patients for a kidney and pancreas transplant. The current arrangements will remain unchanged although it was recognised that there might be occasions when units need to change the requirement for a particular patient being registered.
- A patient cannot be registered at more than one centre for a kidney and pancreas transplant. However, patients can be registered on the national kidney transplant list for a kidney-only transplant at a non-pancreas transplanting centre. The kidney and pancreas registration can only be held locally by the kidney and pancreas transplant centre to which the patient has been referred.
- Amendments were agreed to the pancreas zoning arrangements to incorporate the addition of Cardiff as a pancreas centre and the proposal that pancreata from Northern Ireland are retrieved by Edinburgh until such time as the liver zones have been reviewed.
- The fast-track pancreas-offering scheme was approved and implemented on 1 December 2004.
- A guidance paper on liver retrieval techniques that are compatible with safe pancreas removal was produced and agreement reached for this to be submitted to the Liver Steering Group for information.

Liver Advisory Group

LAG met on 10 November 2004

- The protocols and guidelines for donor liver use were reviewed and the amended version is available on the UKT website.
- The protocol for splitting of livers was amended - splittable livers will be provisionally placed at the time of the donor offer, if appropriate, rather than when the liver is being or has been split. This will enable the shared use of splittable livers in the usual offering sequence.
- In September 2004, as a result of funding of research and cost savings, the National Specialist Commissioning Advisory Group (NSCAG) decided to transfer responsibility for the Liver Transplant Audit from the Royal College of Surgeons to UKT for one year from 1 April 2005. Following representations to NSCAG the proposal to move the audit to UKT was reversed in October 2004 and the audit will now remain with the RCS until March 2006. During this time the longer-term arrangements are to be reviewed.

- Under the European Union Tissue and Cell Directive, which will become operative in April 2006, any tissue stored for more than 36 hours will need to be stored in licensed tissue banks. In the meantime any existing storage is subject to guidelines issued by the Medicines Healthcare Regulation Agency (MHRA). Liver units will need to either: seek exemption from accreditation as a tissue bank, continue with current methods but seek accreditation as a tissue bank or use the services of an accredited tissue bank, such as a local bone marrow unit or pancreas islet unit.
- Changes to the liver retrieval zones were approved, subject to a frequent review of donor activity against contract size. The new zones were implemented on 4 January 2005.
- Two changes to the fast-track liver offering system were approved for implementation from 4 January 2005. The UKT Duty Office no longer has to receive a response from each centre and if no reply is received then it will be assumed that the centre wishes to decline the offer. Also, provisional acceptance of the offer is not acceptable. A definite response must be given.
- An informal sharing agreement for asystolic livers between local centres rather than through the offering system was proposed. The group agreed that centres should continue to either fast-track these organs if they were not to be used locally for either Group 1 or Group 2 patients, or offer them locally rather than discard them. This would minimise travelling times for these marginal organs.

Kidney & Pancreas Advisory Group

KPAG met on 1 December 2004

- Centre specific data to appear on the UKT website is currently being assessed to ensure the clarity and appropriateness of the information.
- A joint meeting of the British Transplantation Society and the British Society for Histocompatibility and Immunology was held to look at possible steps that laboratories could take to minimise cold ischaemic time. KPAG accepted a proposal that all renal transplant units should commence a thorough audit of all the components of cold ischaemic time. UKT will provide statistical analysis of the total data set to allow each centre to assess relevant local factors.
- A major instance of non-compliance with the National Kidney Allocation Scheme was reported to KPAG. Assurances had been received from the unit director concerned that appropriate action had been taken within the trust and that the unit was committed to the scheme.
- The historical record of patients should not be altered when units appropriately suspend patients from the transplant list but then don't reactivate them at the correct time due to an administrative error within the transplant unit. However, UKT will endeavour to recalculate and reallocate the missing points.
- Kidneys are to be offered provisionally, prior to retrieval, in order to reduce cold ischaemic time and enable units to assess the suitability of the donor, based on the clinical information.

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The unit should confirm whether they would accept a definitive offer once anatomical details are known. Units must inform the UKT Duty Office of the donor HLA type as soon as possible to enable a provisional offer to be made.

- Despite inferior transplant survival for transplants from non-heartbeating donors in early years, results for transplants in 2002/03 show that transplant survival of both non-heartbeating and heartbeating donor kidney transplants is now comparable.
- An extraordinary meeting of KPAG in February 2005 met to consider the proposals from the task force working on the revision of the National Kidney Allocation Scheme, and the working party on equity of access to transplantation. A separate report on this work will be included in a future bulletin.

Patients' Forum

Patients' Forum met on 19 January 2005

- In light of the establishment of the new authority (NHS Blood & Transplant) there is likely to be a review of the advisory group structure. The importance of the involvement of both patients and the public in the work of the new authority, both in a patient group and through representation on the authority's advisory groups, was stressed.
- Members debated issues that could affect the numbers of transplants, in particular legislation within the new Human Tissue Act.
- Members also debated issues around altruistic living donation – see page 11.

NEWS

Going the extra mile in Oxford

Oxford transplant co-ordinators Ella Poppitt, Helen Challand and Mike Sturgess have been busy raising awareness of organ donation in the city as part of the 10th anniversary of the NHS Organ Donor Register. For three months the city's buses could be seen emblazoned with "Go the extra mile. Join the organ donor register".

And in a bid to encourage football supporters to sign up, the team spent an evening distributing leaflets at Reading FC's Madjeski stadium. Advertising banners by the side of the pitch, an article in the club magazine and messages flashed onto the stadium's giant screen helped to strengthen the campaign.

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Accessing the ODR

Thank you to the 12,050,000 people – over 20% of the UK population – who have said they want to help others to live after their death by joining the NHS Organ Donor Register.

Between 1 September and 31 December 2004, 293 requests were made to access the register:

- 24% of all cornea donors and
- 18% of solid organ donors

were found to have registered their wishes on the ODR.

The ODR is accessible by authorised NHS staff and should always be consulted to find out if the potential donor has registered his/her wishes prior to discussing organ donation with the family. The option of donation should still be discussed, regardless of non-registration.



Lord Mayor of Oxford, Bryan Keen, with Mike Sturgess and one of the Oxford buses.

The team also secured media coverage in the form of a local radio campaign. A specially recorded advert was broadcast on local radio station, Fox FM. This helped to promote the organ donation message to over 200,000 listeners every week.

Mike Sturgess said: "Although it's early days yet as far as seeing results in new registrations, the feedback we've had has been excellent. We've had some really positive comments from people in the hospital and beyond."



Professor John Armitage, Director of the CTS Bristol Eye Bank (centre), with John Massie (left) and Roger Payne (right) of Rotary helping to promote the new leaflet.

The gift of sight

A new leaflet has been produced promoting cornea donation. Every year cornea transplantation helps to restore the sight of more than 2,000 blind and partially sighted people. But the shortage of donated corneas means that many more could be given the gift of sight if there were more donors.

The leaflet, *Organ donation. The gift of sight*, includes case studies and a registration form for the NHS Organ Donor Register.

A poster to promote cornea donation, using the same design, has also been produced.

The Assembly for Wales has funded bilingual versions of both the leaflet and poster.

The leaflets and posters are being distributed to areas with eye retrieval centres. UKT will also be linking up with local Rotary groups and local opticians to promote awareness of the need for corneas.

All materials are available from the Organ Donor Line and the leaflets are also available on the website, through the new campaigns section.

New campaigns section of the website

A new section of the website devoted to campaigns is due to be launched during April. It will include a catalogue of all UKT's leaflets and promotional items, allowing users to see the whole range of materials that is produced.

UKT will eventually be able to offer an online ordering facility, but initially users will still be signposted to the Organ

Donor Line by phone, fax and email.

The new section will also include updates on all UKT campaigns, from the 10th anniversary campaign to work with black and Asian communities. Over the coming months we will be adding case studies showing how all kinds of different people are helping to promote organ donation: from the mother who

puts organ donation leaflets into organic veggie box deliveries, to the employer who has taken up UKT's email campaign.

We hope the new campaigns section will be a good resource and an inspiration for both seasoned campaigners and newcomers looking to "do their bit".

Publicity pack

A new publicity pack full of guidance and ideas on promoting awareness of organ donation will shortly be available from UKT. It has been written by the Communications team at UKT and will be a great resource for anyone wanting to find out about, or already involved in, promoting organ donation.

The pack includes sections on the media – making contact, what makes a news story, how to write press releases, and how to deal with journalists when they want information from you. It also includes sections on using photographs, organising events, attending exhibitions, seeking funding, promotional ideas and further resources available from UKT.

The pack will be available from the Organ Donor Line, but limited to one copy per order.



Organ Donor Line 0845 60 60 400 – for all leaflets and promotional items

Scotland gives the gift of life

The transplant unit in Edinburgh was the driving force behind a **massive public awareness campaign in Scotland**.

Scottish TV and supermarket chains, Sainsburys and Scottish Co-op, joined forces to encourage more people to join the NHS Organ Donor Register.

The campaign kicked off with a half-hour television documentary in early December. Stories from patients, staff and donor families were screened on Scotland Today, the country's leading television news programme, every weekday for seven days, with regular live links to the 270 stores taking part. Some of these interviews will be made available on UKT's website through the new campaigns section.

Press and radio ads running throughout December helped boost the campaign's impact. TV presenter Lorraine Kelly, actor, Brian Cox and singer, Sharleen Spiteri, were amongst a host of celebrities lending their personal support.

Jen Lumsdaine, who co-ordinated this ambitious campaign, said: "It's been such hard work, but really satisfying to see it all come together with huge amounts of TV coverage. The response we've had to the programmes has been so positive, and I'd really like to thank everyone who's helped us."



Nick Dixon, Presenter of Scotland Today and John Forsythe, Consultant Transplant Surgeon, Edinburgh, with some of the completed registrations at the end of the Scottish campaign.

The final registration figures from the campaign aren't yet available. But already over a quarter of all Scots are signed up to the register – that's 1.29 million people. Scotland now boasts the highest proportion of its population on the register compared with any other region in England and Wales.

Fiona Wilkinson, Bolton donor liaison sister and Dr Sarah Thornton, consultant anaesthetist, ran a **series of presentations at Oldham Sixth Form College** during one day in January. Every student at the college – that's 2,000 young people – has now seen the presentation, thanks to the innovation of the students in videoing

Fiona and Sarah in action and screening the videoed presentation during classes.

"The response of the students was fantastic – I was impressed by their interest and enthusiasm," commented Fiona.

"Nearly half the students at the college are Asian, and the college had taken care to prepare all the students before our visit. They were responsive and open-minded, with very positive views on organ donation."

The college is continuing to promote organ donation by providing links from their intranet to the UKT website. Fiona aims to spread the word about the most positive aspects of the visit to other transplant co-ordinators for future presentations.

David Stevens, Chief Constable of Essex Police, is leading a **campaign to encourage the county's police force to join the register**.

The police intranet site hosts a special feature to promote organ donation, with a link to UKT's website. Posters, leaflets and other promotional items have been distributed amongst officers at the ten main stations in the county.

"The campaign is already proving successful with well over 200 responses to date," said David White, Internet Manager. "We hope to keep the momentum going by providing regular updates on the intranet site."



Oldham students are open-minded and positive.