bulletin

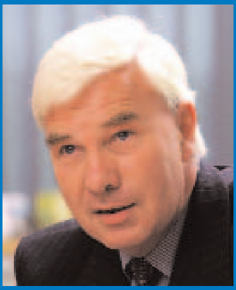
NHS
UK Transplant

The newsletter for everyone involved in organ transplantation and donation
Issue 59 Summer 2006

In this issue: Research into end of life decision-making. New black and Asian research shows there is still a long way to go. Potential for paired living kidney donation in the UK. International experiences of living donation. Appointment with Robert Bonser. Scottish campaign receives award. Campaign drives motorists. 10th anniversary campaign shortlisted for PR award. UKT business plan.

UK Transplant is part of NHS Blood and Transplant

CHIEFLY



The provisional figures for donor and transplant numbers for the financial year 2005/6 are now available on UK Transplant's website. The pattern of the last two or three years has been repeated and the trends are becoming ever clearer.

Areas of improvement are being further enhanced whilst the areas of disappointment are ever more serious. Fundamentally, organ transplantation from living donors and non-heartbeating deceased donors continues to increase markedly whilst for donation from heartbeating donors the reverse is true.

This is reflected in a small but welcome increase in overall kidney transplant numbers but a fall in the number of liver and heart transplants. For these latter groups of patients the situation is dire and, in particular, the liver transplant units are now under extreme pressure.

There were 586 deceased donor liver transplants in 2005/6 compared with 649 in 2004/5 and a peak of 705 in 2002/3. The liver waiting list at the end of March 2006 stood at 365 patients – by far the highest figure on record.

From UK Transplant's perspective these figures provide a stark reminder of how much more needs to be done. The key is to understand what has worked so far and what has not been so successful, and to identify problems and failings with existing arrangements. Not everything is within our sphere of influence and continued public and political support for donation is essential.

The results of the first two full years of the national Potential Donor Audit (PDA) have now been published in the British Medical Journal and the 30-month results were presented at the British Transplantation Society meeting in March in Edinburgh. They provide an invaluable insight and give clear pointers to the next steps.

Firstly, the data show that over 30% of patients in intensive care units whose clinical condition suggested that death of the brain stem might have occurred were not formally tested. No doubt some of these patients would not have met the criteria and there were appropriate clinical reasons for not testing others, but it seems likely that a proportion of them could – and probably should in their own best interests – have been tested, leading to certification of death and the potential for heartbeating donation.

Secondly, there is a (relatively small) group of patients who met the criteria for death after brain stem tests in whom there was no record of discussion about organ donation with the relatives. However this does not always mean that donation was not considered.

On both these points the current PDA format does not provide enough detailed information. It is therefore being reviewed and developed in order to look in much more detail at these two areas. What is known – very clearly – is that the relatives of 40% of potential donors refuse consent, and that this usually reflects the wishes of the relatives themselves. Whether the Human Tissue Acts, with their emphasis on the primacy of the wishes of the deceased, if known, will change this – remains to be seen.

Initial experience following the appointment of in-house donor co-ordinators in a small number of major ICUs in the UK is undoubtedly encouraging. It is UK Transplant's intention to extend these posts to all the ICUs with significant numbers of potential donors.

Funding has not yet been identified for all these posts but their introduction is seen as crucial. Their possible impact is considerable both in working with ICU clinicians to optimise potential donor identification and referral and in achieving a marked reduction in the relatives' refusal rate.

The recently established Donation Advisory Group at UK Transplant – chaired by Dr Martin Smith from London – will play a crucial role in developing the PDA and in implementing the changes that we believe are essential.

Chris Rudge

Chris Rudge
Managing & Transplant Director – UK Transplant

bulletin
IS PUBLISHED QUARTERLY ISSN 1472-0507
Copy date for Autumn 2006 edition 4 September 2006
Contributions should be sent to Clare Hanson-Kahn

UK Transplant, Fox Den Road, Stoke Gifford, BRISTOL BS34 8RR
Tel: 0117 975 7562
Fax: 0117 975 7515 Email: bulletin@uktransplant.nhs.uk
Designed by Bob Design and Marketing www.meetbob.co.uk

Front cover picture:
Chitty Chitty Bang Bang stars help promote UKT's campaign aimed at motorists (see page 6).

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

UK Transplant division business plan

UKT has produced its business plan for 2006/07 and the key targets are to:

- continue to work to decrease relatives' refusal rate by completing the implementation of 14 funded in-house co-ordinators posts, working with the Intensive Care Society to ensure mechanisms are in place for 'early referral' to donor transplant co-ordinators and to implement collaborative requesting nationally
- increase the number of people registered on the ODR to 13.9 million by exploring new ways of promoting access to the register with Government departments and health administrations, continuing to work with key partners to distribute mailings, piloting city-based multi-media campaigns and developing further targeted web-based campaigns
- maximise patient safety and patient and graft survival by monitoring the new Kidney Allocation Scheme, and monitoring the liver, cardiothoracic and pancreas organ allocation schemes and zonal arrangements to ensure allocation is efficient and equitable
- ensure that the data collection and validation process continues to provide relevant data of the highest quality to inform analysis and audit activity
- collaborate with the transplant community and other organisations to maximise the potential of the National Transplant Database
- investigate factors associated with organ donation in order to increase the numbers of organs available for transplantation through the Potential Donor Audit and other audits to identify best practice and reasons for missed potential
- support the Corneal Transplant Service's operations in the provision of corneal tissue storage, preparation and allocation
- continue to performance manage 13 non-heartbeating schemes, 25 living donor schemes, 11 transplant co-ordinator schemes, 8 eye retrieval schemes, 2 living donor schemes, 14 in-house co-ordinator schemes and the remaining donor liaison schemes
- explore the potential for future development of non-heartbeating and living donor schemes.

UKT named as running one of the UK's best PR campaigns

The campaign to mark the 10th anniversary of the NHS Organ Donor Register has won a top public relations accolade. The Chartered Institute of Public Relations has named it as one of the best PR campaigns of last year and has short-listed it in the healthcare section for one of its annual Excellence Awards.

A record 724 entries were received this year across 26 categories and UK Transplant is competing alongside five others in the same section for the top prize.

The Excellence Awards recognise and reward best practice in public relations throughout the UK and acknowledge personal and team achievement at the highest professional level. The winners will be announced at a special event in London in July.

UK Transplant Media and PR Manager, Maxine Walter, said: "This is a great achievement as our work has been judged to the highest standards by a select group of the UK's leading PR experts.

"The honour also reflects the widespread support and involvement in the campaign of many others including transplant co-ordinators, charities, individuals, MPs, commercial and public sector organisations – so thanks to them all."

NHSBT faces the future

A leaflet aimed at staff, hospitals, politicians and the general public, setting out the challenges for NHSBT over the coming months and years, has been produced and is included with this *bulletin*.

In the leaflet, Bill Fullagar, NHSBT Chairman, says: "We have many reasons why we need to evolve and adapt; not least of these is to meet the challenges of the constantly changing environment we operate in.

"Only through modernisation will we meet the challenges facing us. But we need to ensure there is no negative impact on patients or hospitals."

For further copies of the leaflet, *Saving and Improving Patients' Lives*, contact: Chris Hartley at NHS Blood and Transplant, chris.hartley@nhsbt.nhs.uk

The tenth anniversary of the NHS Organ Donor Register had a high profile kick off in Trafalgar Square.

Human Tissue (Scotland) Act 2006

The Human Tissue (Scotland) Act 2006 received Royal Assent on 16 March 2006, and it will come into force on 1 September 2006, in line with the arrangements for the rest of the UK. Will Scott, Transplantation Policy Lead at the Scottish Health Department, gives more detail.

The Scottish Act rests on the concept of "authorisation" which parallels the principle of consent in the Human Tissue Act 2004. Authorisation embodies the idea that people have the right during their lifetime to express their wishes about what should happen to their bodies after death, and to have those wishes respected.

Adults (those aged 16 and over) and children who are aged over 12 at the time of their death can give their authorisation, which in most cases will take the form of having put their name on the NHS Organ Donor Register. The 2006 Act is written so as to make sure that all existing Scottish adult names on the register will count as authorisations under the new legislation. Where someone has authorised a number of possible uses of their body after death, the Act makes clear that authorisation for transplantation takes priority.

At its very outset, the Act places a specific duty on the Scottish Ministers to promote, support and develop programmes of transplantation, to promote information and awareness about donation for transplantation and to provide assistance and support to anyone providing a service relating to transplantation. This exemplifies the positive tone, which the Scottish Executive wished the legislation to have, and the Department will use the guidance it is preparing to emphasise that these duties apply to the whole of NHS Scotland.

The Act supports current good practice, such as the gaining of authorisation over the telephone by tissue co-ordinators.

It also paves the way for the Regulations which will allow non-registered medical practitioners to be trained to retrieve tissue for transplantation purposes.

The Scottish Executive will be working closely with UKT and the transplant co-ordinators to develop the new forms and procedures which the Act will make necessary, and hopes to be able to update the *Organ Donation Teaching Resource Pack* as an effective way of increasing public awareness of the opportunities offered by the new legislation.

The Executive is confident that the new legislation in Scotland should lead to a marked increase in organ donation rates in Scotland.

Transplant Games

The British Transplant Games 2006 will take place at the University of Bath from 17 - 20 August, a weekend of sport, fun and friendship for transplant recipients.

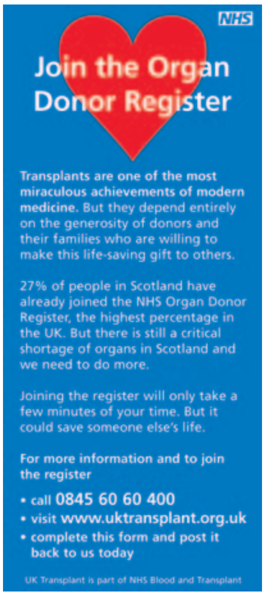
The programme will include a wide variety of sports including track and field, swimming, badminton, cycling, tennis, bowls, darts, snooker and archery. The 16th Transplant Torch Relay from Leicester to Bath will mark the event beginning at the venue of last year's transplant games and carrying on to this year's venue in Bath.

For more information contact Mary Twomey, Administrator for Transplant Sports Association of Great Britain on tsagb@tsagb.org or visit www.tsagb.org

NHS Scotland employees urged: "don't throw it away"

166,600 NHS Scotland employees are being sent organ donation flyers with their payslips in June, in an initiative being supported by the Scottish Executive, the Scottish Transplant Co-ordinators Network (STCN) and UK Transplant. The campaign is being supported by all the regional health boards and special health boards, NHS 24 and National Services Scotland.

With the support of the health-board's communication teams, internal publications and intranets are being used to prepare staff for the flyer in June. The STCN has also produced a poster which will be displayed throughout June urging NHS Scotland employees to use this opportunity and sign up to the NHS Organ Donor Register.



Join the Organ Donor Register

Transplants are one of the most miraculous achievements of modern medicine. But they depend entirely on the generosity of donors and their families who are willing to make this life-saving gift to others.

27% of people in Scotland have already joined the NHS Organ Donor Register, the highest percentage in the UK. But there is still a critical shortage of organs in Scotland and we need to do more.

Joining the register will only take a few minutes of your time. But it could save someone else's life.

For more information and to join the register

- call 0845 60 60 400
- visit www.uktransplant.org.uk
- complete this form and post it back to us today

UK Transplant is part of NHS Blood and Transplant

West of Scotland Transplant Co-ordinator, William Murray, who has been organising the campaign, said: "This campaign is very exciting given that it follows on closely from the Scottish Executive's own hard hitting public campaign and culminates just prior to National Transplant Week in July. Scotland already leads the way with 27% of the population registered and we're hoping that this campaign will help increase that figure even further."

BBC DoNation season wins media award

Casualty stars supported the BBC's DoNation season.

The BBC's DoNation season has been awarded a "Peabody". The Peabody is an international media award and recognises distinguished achievement and meritorious public service by stations, networks, producing organisations and individuals. Other BBC winners were *Bleak House* and *Children of Beslan* so the DoNation season is amongst the best.

A spokesperson from the BBC, acknowledging the award, said: "Public service campaigns rarely combine the potential and power of electronic media – TV, radio, online, interactive – in ways as effective as this concerted appeal for organ donors."

Net benefit from shopping link

An online initiative designed to provide more information about organ donation and encourage registrations has been launched by UKT's Marketing and Campaigns team.

Two online shopping sites ask visitors whether they would like information about the NHS Organ Donor Register sent electronically. They can elect to receive a specially designed email, which contains case studies and information about organ donation. This email also has a link to UKT's website to enable them to find out more and register online if they wish.

Within the first two weeks of the project launch, the two sites have generated over 2,000 applications to register online.

Angie Burton, UKT's Campaigns & Marketing Manager, said: "We're piloting this scheme and will evaluate it fully once it's complete. But it already seems that finding out more and joining the ODR is proving popular with online surfers. This could be a really cost-effective way to encourage more people in the UK who 'just haven't got round to it', to join the register."

Visitors are guided through a series of information-gathering questions to provide lifestyle information, and they can then request more information on a range of different products and services.

At the end of the questionnaire, UKT provides summary information about organ donation and why it is important to join the register. At this point people can tick a box to receive more information and within 24 hours they are sent UKT's interactive email.

Visit www.emailinform.com and www.myoffers.com to see for yourself.

Joint NBS & UKT clinical audit & research conference

Tuesday 7 November 2006

Since 2000 the NBS has held an annual clinical audit conference around different themes. For the last couple of years it has been open to delegates from the wider NHS. This year, UKT and the NBS are joining forces to hold a joint one-day conference in November with the theme "Creating an environment where best practice can flourish".

The conference aims to:

- share information on the evidence base of transfusion and transplantation
- disseminate information on current practice
- provide opportunities to understand how quality is improved by multidisciplinary teams, and the interventions used to implement change
- identify how patient involvement can provide direction for clinical quality
- explore different approaches to identifying clinical risk factors and changing behaviour in the fields of blood donor care, transfusion and transplantation.

The conference will be split into plenary sessions and breakout sessions for different areas of practice such as quality improvement, training and education. There will be a poster exhibition of clinical audits and examples of sharing best practice with prizes for the best posters.

Call for abstracts

Abstracts are invited for posters or oral presentations illustrating how best practice can be achieved through research, clinical audit and quality improvement. For further details please contact Karen Sutcliffe on 0113 2148611 or email karen.sutcliffe@nbs.nhs.uk

Closing date for submissions:
30 June 2006
Conference: 7 November 2006

Joint campaign continues drive for motorists

A UK-wide campaign to encourage even more motorists to sign up to the ODR is being supported by Britain's favourite car and two on-screen rivals.

Across Great Britain – England, Wales and Scotland – flying motor *Chitty Chitty Bang Bang* is highlighting a campaign that will see more than six million special leaflets being sent to motorists between April and July, thanks to a partnership between UK Transplant and the DVLA.

The leaflets – *We've signed up. Have you?* – are accompanying new and replacement driver's licences as well as vehicle tax reminders.

Live kidney donor Sue Corbett (left) and transplant co-ordinator Eleanor Donaghy urge motorists in Northern Ireland to give the gift of life.

Chitty Chitty Bang Bang and the cast of the famous stage musical, took time out from their current UK tour to help publicise the new campaign that also aims to say thank you to the almost six million motorists who have already joined the ODR when they applied for their driver's licence.

In Northern Ireland, rival TV presenters with personal experience of the benefits of organ transplants are backing a similar UK Transplant campaign run in partnership with the DVLNI.

BBC Newsline's Stephen Watson received a kidney from his father in 1990 after being told both his kidneys were failing. Sue Corbett, (pictured above), a regular on Ulster TV, donated a kidney to her husband Robin in 2004.

Both are urging motorists in the Province to pledge the gift of life. One million copies of the UKT's leaflet are being sent out over the next 12 months to drivers with their annual vehicle tax reminder, while leaflets will also be sent to up to 200,000 drivers renewing their licence each year.

Explaining the reason for the latest campaign, UK Transplant Director of Communication Penny Hallett said: "We believe many more drivers are willing to help others – we just need to reach them."

New large order process at the Organ Donor Line

A new ordering process is now in place at the Organ Donor Line (ODL) setting higher order limits for most leaflets. The new limits should support the campaigns and promotional activities of most callers, whilst helping UKT manage its stock levels and minimise wastage.

The ODL will no longer be able to take orders above the new limits. If you are planning a major, large-scale promotion you can contact campaigns@uktransplant.nhs.uk and the campaigns team will advise on appropriate quantities for your event.

For orders phone the Organ Donor Line on 0845 60 60 400.

10th annual symposium in Leeds

Transplant co-ordinators from Leeds, Liverpool and Manchester are organising their 10th annual symposium on organ donation and transplantation.

The programme will include issues around diagnosing brain stem death, tissue donation and retrieval, non-heartbeating donation, islet cell transplantation, and the recent advances in face transplantation. There will also be a debate about alcohol and the liver and discussion about donor family and recipient experiences.

Date: 14 September 2006
For more details email Maria Walsh: maria.walsh@leedsth.nhs.uk

Scottish campaign receives award

The Scottish campaign used blunt advertising to spur people to register.

The Scottish Executive's awareness-raising campaign has recently been recognised by the Fresh Media awards. The awards acknowledge fresh ideas and innovative thinking and the Scottish Executive's campaign was "highly commended". Frances Swanwick, who ran the campaign on behalf of the Scottish Executive, describes the campaign.

The Scottish Executive has been running campaigns to raise awareness of the issues around organ donation for a number of years. Over the years we have noticed that organ donation has received an incredible amount of press coverage. Journalists are hugely interested in real life case studies, stories about local people either running out of time, or in some cases, being saved and given a new lease of life.

Traditionally we have used advertising as the backbone of our campaigning, with PR as a secondary communications medium.

This year, with a limited budget, we had to adopt a radical approach. We decided to use PR as the foundation of the campaign, and advertising to work off the back of it.

Our planning "idea" was brutally simple but quite risky. We would only advertise when we had PR coverage and we would advertise on the very same day.

The campaign ran from November 2005 to February 2006 and the results show that our approach paid off. Scottish registrations were up 46% during the campaign quarter. The first two months proved more than five times more effective than two months of advertising in 2004.

We got a total of 18 substantial stories in 11 titles, achieving an estimated 12 million "opportunities to see" (OTS). Direct response advertising ran alongside the PR stories in every single title, as well as on subsequent days. The press advertising reached an estimated 91% of all adults, with an estimated seven OTS.

PR introduced highly moving stories of local people and this, in turn, created awareness of the issues around organ donation, and generated sympathy. The advertising that accompanied it was deliberately less gentle – it bluntly told the public that if they weren't on the register, lives would be lost needlessly.

ORGAN-ise tops the charts

***Organ-ise*, UKT's online game highlighting issues about organ donation and transplantation, is proving one of the most popular online games in the world.**

After a winter break the game is back online, and in one week in March it attracted over 24,000 players, taking it to number two in the world "viral charts".

Organ-ise, developed to support UK Transplant's tour of freshers' fairs last year, has proved a hit with students as they play the role of a transplant surgeon deciding who should benefit from donated organs – against the clock.

Over 350,000 people have viewed the game, which includes a link to the sign-up section of UK Transplant's website. You can see the game at www.organ-ise.org.uk

Register reaches 13 million

bulletin readers will be interested to know that there are now 13 million people on the NHS Organ Donor Register – 22% of the UK population. This is an important milestone for the ODR and local efforts to help raise awareness and encourage registration are much appreciated.

Transplant Week 9 - 15 July 2006

This year National Transplant Week, organised by Transplants in Mind (TIME), aims to appeal to a wide range of "ordinary people" with the theme: you don't have to be a hero to save lives.

Spare Parts Theatre Company will be treading the boards to promote organ donation with the launch of their new play, *Better*. A frank and honest story about love and life on the transplant waiting list, written by playwright and kidney transplant patient Glenn Mortimer, *Better* will be performed from 10 -15 July at The Rosemary Branch Theatre in London. The opening gala night will include poetry, theatre and music inspired by patients' experiences of dialysis and transplantation.
More information can be found at www.rosemarybranch.co.uk

Heart and lung recipient Diana Sanderson will launch her new book on transplants, *Will I still be me? A journey through a transplant*. Diana wrote the book to help others going through the transplant experience, and to publicise the good that organ donation can do. The book will be published in early July by Day Books.

GMTV will be focussing on organ donation all week, covering different aspects of transplantation and organ donation and talking to donor families, recipients and people waiting for transplants.

Other events include a sponsored pier-to-pier walk from Brighton to Worthing and a thanksgiving service in Birmingham organised by the Donor Family Network.

Travel West Midland buses will be displaying the Transplant Week poster, and producing two million specially printed bus tickets urging people to "go the extra mile" and join the NHS Organ Donor Register.

For more information about Transplant Week and to order posters contact Sue Johnstone at TIME, tel 07702 853189 or email sue@transplantsinmind.fsnet.co.uk

FEATURES

Using international experiences to learn about living donation

In March of this year, Guy's Hospital held its second living donor course. Delegates came from all over the UK, Europe and as far afield as Japan, and included transplant co-ordinators, doctors, nurses and managers. Here Nizam Mamode, consultant surgeon at Guy's Hospital, reports on a day, which was both stimulating and informative.

The course aimed to provide the basics for those starting out in living donation, but more importantly to allow discussion of a number of key issues in living donation.

Delegates discussed a number of difficult case scenarios and heard the faculty give their, often differing views, on management of these patients.

James Gloor, of the Mayo Clinic in the USA, discussed marginal donors and presented data which showed that hypertensive donors can have a successful outcome for both donor and recipient, whilst obese donors have more complications but an acceptable short-term donor outcome in terms of GFR and microalbuminuria (obese in the US meaning BMI >35!).

At the cutting edge as ever, Nigel Heaton from King's College Hospital, presented excellent data on the King's experience of living liver donation and discussed when this was justified.
A potential donor mortality of 1 in 250, as well as significant donor morbidity, invoked understandable reluctance from the surgical community, but it was clear that for some recipients this was the only hope.

A long debate took place over forthcoming changes as a result of the Human Tissue Act. After Chris Rudge of UKT had given a detailed explanation of these, we heard from Bernadette Haase, Director of the Dutch Transplant Foundation, about the paired exchange scheme, which has been implemented in Holland.

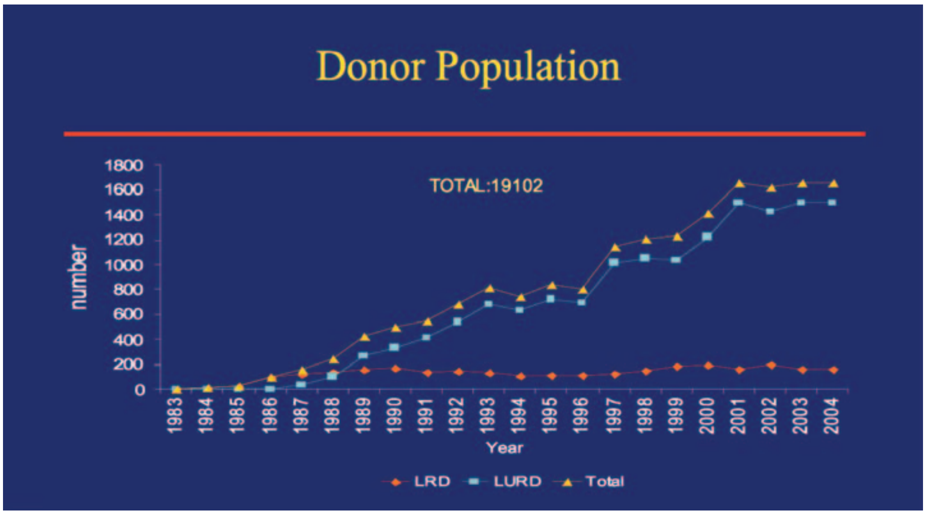
Seven centres throughout Holland had participated, and donors were asked to travel to the recipient's centre, with simultaneous operating times. Anonymity was preserved and, interestingly, donor costs, including family travel and accommodation, were met. 116 pairs had been listed due to a positive cross-match or blood group incompatibility and exchanges had been possible in about 50% of cases (with six 'triplets').

The system is certainly working well in Holland but has required a high degree of co-operation and co-ordination between centres.

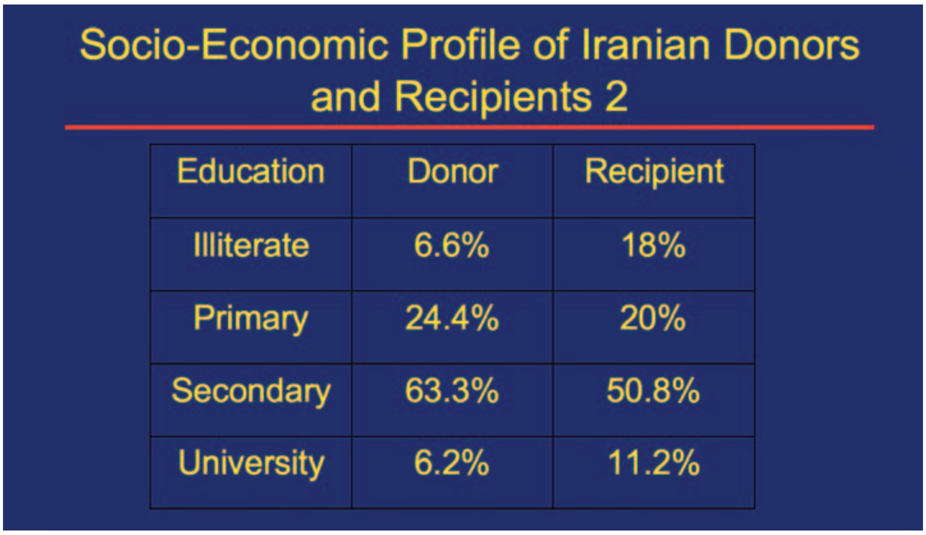
Shideh Pouriah, a Guy's nephrologist with Iranian connections, presented a challenging summary of the paid living donation scheme in Iran. There the Government compensates donors financially and with health insurance, in a controlled and regulated fashion.

This has resulted in over 19,000 transplants over a 23-year period, and has meant equitable access to transplantation and an end to transplant tourism. Results were excellent and interestingly the socio-economic status of donors did not differ from that of recipients. Although there are many ethical and practical problems, including coercion and exploitation, it was suggested that this may be a useful model for a developing country with limited resources.

James Gloor summarised the Mayo's experience of blood group incompatible donation and desensitisation, and compared regimes using plasma exchange, IvIgG, ATG and rituximab. His conclusion was that in positive cross-match patients, low initial titres (1:4 or less) indicate likely success irrespective of the method used, whilst high titres (1:32 or more) indicate a high risk of failure, again irrespective of the method used. A combination of plasma exchange and IvIgG might be best for those patients with mid-range titres, and this appears to be better than high dose IvIgG.



Comparison of unrelated donors and related donors in Iran (source: Dr Fazel and Dr Pouriah).



Socio-Economic Profile of Iranian Donors and Recipients 2

Education	Donor	Recipient
Illiterate	6.6%	18%
Primary	24.4%	20%
Secondary	63.3%	50.8%
University	6.2%	11.2%

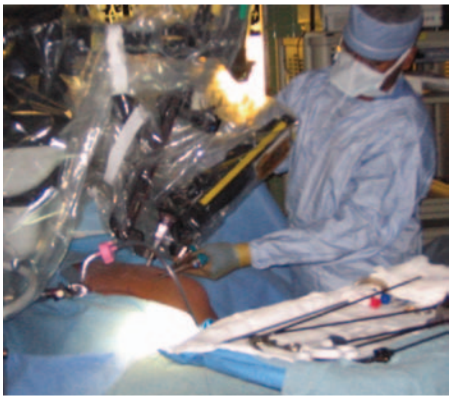
Comparison of socio-economic groups of donors and recipients in Iran's paid donation system (source: Dr Fazel and Dr Pouriah).

In terms of blood group incompatible transplants, good graft survival (89% at one year) has been achieved. A study of 34 patients in the Mayo showed that recipient splenectomy was probably unnecessary, and again, baseline antibody titre is important, with rejection being uncommon with a titre of 1:64 or less.

In the panel discussion that followed, it was clear that some patients will benefit from a paired exchange scheme while for others an antibody removal or desensitisation programme will be best; this will depend on titres, blood group and urgency of transplantation amongst other factors.

Other highlights of the course included a live link to theatre to watch a laparoscopic donor nephrectomy, a presentation on living pancreas donation (the conclusion was that it was not necessary or justified in the UK), and a talk on stem cells for transplantation from Paul Shiels, of Glasgow University.

With rapid developments in cell therapy, animal models for stem cell transplantation (both allograft and xenograft) already exist for diabetes, and the hope is that these may offer solutions for more complex solid organs in the future.



Credit: Nizam Mamode

The Da Vinci robot in use during a live donor nephrectomy.

In summary, it was clear that living donation is expanding dramatically and that new developments are appearing at breakneck speed. It remains an exciting and challenging field and, above all, it is a great privilege to be involved.

Organ donation: gift of life or sacrifice?

In 2004 UK Transplant commissioned a 12-month study to explore the end of life decision-making by families who had declined organ or tissue donation. This is the first detailed investigation of its kind in the UK, carried out by the University of Southampton.

Data for the study was collected from 26 relatives of 23 deceased individuals who chose not to donate their deceased relative's organs for transplant. Participants were recruited via three staged media campaigns in large urban conurbations and through health professionals in hospital trusts.

The research set out to fulfil stated objectives and the main findings are set out in a final report and a summary document, both entitled *Exploring the end of life decision-making and hospital experiences of families who did not donate organs or tissues for transplant operations* and available from the University of Southampton.

The report presents a number of findings and makes recommendations for both policy and practice and for education and training.

The research is based on detailed interviews with bereaved families.

Previous studies have linked poor hospital care of the deceased and family to a negative donation decision. However, this study found that, overall, participants were positive about the care that they and their critically ill/injured relative received and the quality of care did not impact on participants' decision-making.

The report states that participants whose relatives had died before 2000 were more critical and did comment on some negative aspects of care such as "being given information in corridors, not being given full explanations and sometimes poor staff attitudes." However, the families whose relatives had died after 2000 "were full of praise for care given in the units where their relative died."

In addition, open, honest and straightforward communication by doctors and nurses helped keep families informed about what was happening. Having someone to answer questions was an important factor in participants' satisfaction with communication and care.

If the families' decision-making was not affected by hospital care, perhaps it was affected by the views already held by the family or the deceased? Some of the findings from the study were unexpected.

The findings indicate that, as shown in worldwide literature and UK Transplant's potential donor audit, if the deceased had stated that they did not want to donate their organs or tissues and the participant knew their wishes, donation did not take place. However, the report ponders: "What is less clear is why so many participants who had positive views of donation and who knew of the positive views held in life by their deceased relatives, declined donation."

Of the 26 participants in the study 12 expressed positive views about donation, compared to nine who expressed negative views about donation. And of the 23 relatives who had died, nine were known to have expressed positive views about donation, compared to seven who were known to have expressed negative views about donation.

The study suggests that donation decisions, made by the family, depend in part on a number of factors converging in a particular situation such as:

- circumstances at the time of death
- information about the donation process
- the timing and manner of the donation discussion
- the family's views about keeping the body intact
- the family's desire not to prolong the suffering of the deceased especially if the deceased had had long-term medical intervention during their lifetime
- the family's need to be with the deceased and to witness the observable ending of life represented by cessation of the heartbeat.

Protecting the body, which related to keeping the body whole and intact was the most frequently recurring theme underpinning a decision not to donate. Fifteen participants said that they could not bear the thought of their deceased relative being "cut up" and used emotive words such as "interfered with", "battered", "a piece of her", "he'd not been touched", "desecrated", "mauled around", "violation" and "butchered".

"Protecting the body... was the most frequently recurring theme"

Participants did not regret their decision to decline donation, but some expressed feelings of guilt and selfishness, which they attributed to: feeling that they were in the minority (ie most people donate), not helping others, not fulfilling the wishes of the deceased, and media pressure to "give the gift of life".

Participants would have liked an opportunity to "explain" or discuss their donation decision with health professionals.

The report argues that we need to look more closely at the "cultural" aspects of organ donation and that the need to protect the body may stimulate a tension between the notions of the "gift of life" as supported by transplant policy and the "sacrifice" of an unscathed body, which must be made if organ donation is to proceed.

The authors suggest that organ donation can be equated to a "sacrifice". They refer to sacrifice "as an offering made valuable by a hard-wrought, difficult-to-relinquish gift" and they cite Mongoven (2003) who proposes that organ donation fulfils the criteria of sacrifice.

The report states: "The bereaved family must make the often very difficult decision to relinquish the guardianship and protection of the corpse to allow the cutting up of the body and the removal of organs, albeit through a standardised surgical procedure, for the benefit of the recipient (Sque et al 2003). Mongoven (2003) suggests that transplant policy which seeks to make donation a commonplace routine may leave the donors and their families invisible with the real costs and benefits of their sacrifice unrecognised."

The report concludes that: "Although the 'gift of life' discourse may remain useful in heightening public awareness about the benefits of donation this is not an adequate framework for understanding what is important for the family at the bedside faced with a donation decision. We argue that such decisions are more closely related to sacrifice. If this is indeed the case, sacrifice provides a potentially valuable theoretical perspective for explaining the decisions of families who choose not to donate. It may also have some value in explaining why in populations where there is high awareness of donation, refusal rates also remain high."

This is one of the first studies to examine in detail the accounts of families who decline organ and tissue donation, and it is a welcome addition to the existing body of knowledge and literature.

The authors suggest that the findings highlight the need for further urgent research to help us understand more about the complex processes underlying donation decision-making, particularly to explore further the importance of the concepts of the "gift of life" and "sacrifice".

The report makes several recommendations for policy and practice and recommendations for education and training of health professionals and awareness raising amongst the general public. UK Transplant will be considering all these recommendations.

The recommendations include a need for:

- a recognition that families of potential organ donors are first, bereaved families, and need to be supported by staff who are educated to work with bereaved people
- a recognition that the outcome of donation decision-making does not necessarily depend on views held by the family about donation but on a number of factors converging in a particular situation
- early involvement of transplant co-ordinators once the potential for donation is realised. The transplant co-ordinator needs to remain available to the family during their decision-making to support them and answer questions
- an expansion and commitment to the non-heartbeating programme, which may help families to donate who wish to be with the deceased and witness the observable ending of life, represented by the cessation of heartbeat
- thought given to the way organ donation is promoted to recognise the contribution of the donor and their family.

The research team comprised Dr Magi Sque and Tracy Long from the School of Nursing and Midwifery at the University of Southampton, Professor Sheila Payne of the Palliative and End-of-Life Care Research Group from the University of Sheffield, and Diana Allardyce, Research Fellow, formerly of University of Southampton.

For further information regarding the report please contact:
Dr Magi Sque, School of Nursing and Midwifery, University of Southampton:
m.r.sque@soton.ac.uk

References:
Mongoven A (2003) *Sharing our body and blood: organ donation and feminist critiques of sacrifice.* Journal of Medicine and Philosophy, 28, 89-114.

Sque M, Long T and Payne S (2003) *Organ and tissue donation: exploring the needs of families.* Final report of a three-year study commissioned by the British Organ Donor Society, funded by the Community Fund, February.

New black and South Asian research

The research confirms that groups want their own specially targeted information.

A new piece of research has highlighted current attitudes amongst black and South Asian people towards organ donation and transplantation. Although black and Asian people are three to four times more likely to need a kidney transplant than the general population, there is still a long way to go in terms of raising awareness in these communities.

Informing black and South Asian people about how organ donation and transplantation affects them and their community has been a key part of UK Transplant's campaign work for several years.

Current statistics indicate that this work is vitally important. South Asians make up 4% of the population and black people make up 2%, but over 13% of those registered for a kidney transplant are Asian and 7% are black.

However, where ethnic origin is known, only 1.4% of those on the NHS Organ Donor Register are of Asian ethnic origin and only 0.4% are black.

In addition, UKT's Potential Donor Audit (for 24 months from April 2003) shows that the relative refusal rate for Asians is 77%, and for black people is 71% compared to 35% for white people. And when it comes to actual donation of cadaveric solid organs, for the financial year 2004/05, 96% of donors were white, while only 1.2% were Asian and less than 0.8% were black.

The South Asian campaign was launched in 1999, followed by the black campaign in 2002. UKT uses specially designed leaflets and posters to appeal to South Asian and black people which highlight why organ donation is so relevant to their communities. The campaigns use a mixture of mainstream communications (eg radio and magazine advertising) and community-based activities (eg promotions at melas) to ensure it reaches as many people as possible.

In an effort to build on and improve this work, UKT commissioned research to assess current attitudes towards organ donation and discover how best to reach black and South Asian people.

During January, February and March 2006, 1,295 Indian, Pakistani, Bangladeshi and Black Caribbean people aged between 18 and 80 years of age were interviewed. The interviews took place in London, Oldham, Leeds, Leicester, Birmingham, Slough and Bristol.

Current awareness

44% of people interviewed agreed with organ donation in principle. The majority of these people were Indian, black and Pakistani. However, overall, 57% of people had not told someone close to them about their wishes. The majority of Bangladeshi people were either undecided (53%) about their views or against donation (31%).

Most groups were in favour of living donation (64% of black people, 60% Indian, 55% Pakistani and 30% Bangladeshi). In common with the rest of the population the majority of people (61%) had heard of the organ donor card but less people (32%) were aware of the NHS Organ Donor Register (ODR). Black people were most aware of the register (43%). This would suggest that a targeted leaflet distribution and poster campaign in spring 2005 had been successful in reaching this group of people.

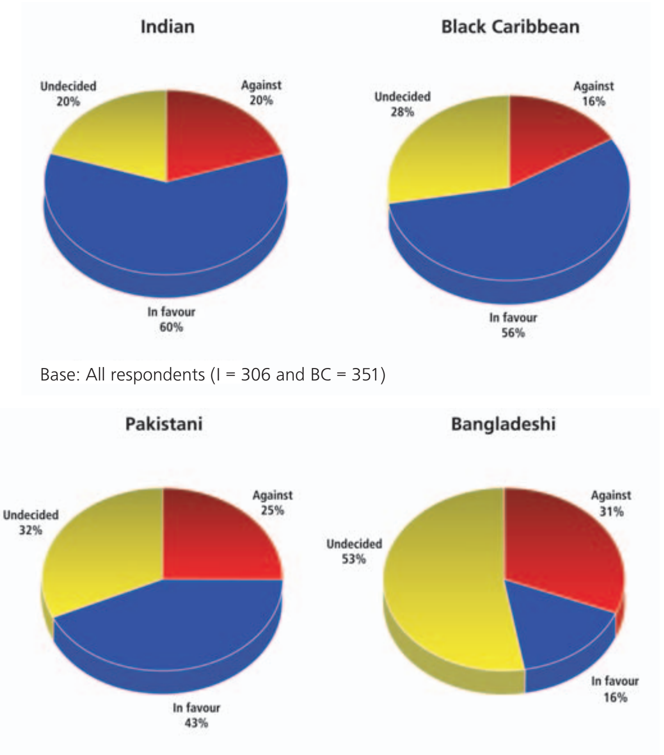
Despite the general knowledge of organ donation there was almost no awareness of how the issue was of specific relevance to black and South Asian people. In fact, the majority of people from all groups thought that black and Asian people were no more likely than white people to suffer from kidney failure.

Many Asian interviewees knew people who have had transplants, had died waiting for organs or are waiting for transplants. However the majority of people did not make the connection between serious disease, increasing organ failure and the lack of organs from Asian communities.

Black people appeared to be even more distanced from the issue of organ donation and almost none had personal experience of transplantation or donation. This could be because the black community was, from their point of view, less cohesive than the Asian so there was less awareness of other black people needing organs within their community.

When asked what would encourage them to join the register, 21% of people not already on the register said "helping someone to live". Knowing someone who needed a transplant would encourage a further 14% and 18% simply needed to know how to register. However a substantial number (26%) stated that nothing would encourage them to join the register.

Attitude towards organ donation in principle

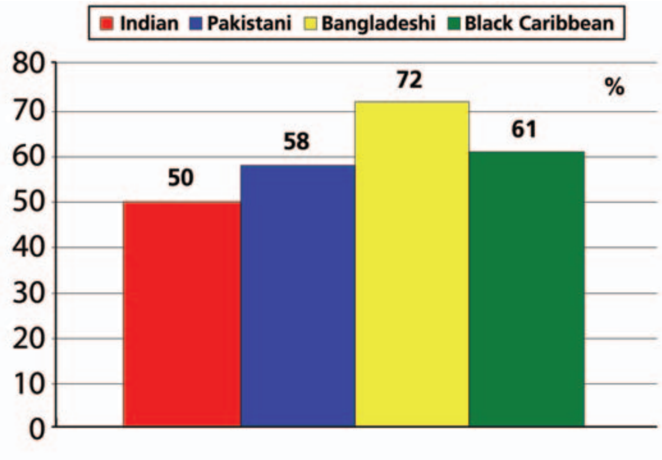


Base: All respondents (I = 306 and BC = 351)

Base: All respondents (P = 306 and B = 332)

Respondents who thought these statements were true

Black and Asian people are no more or no less likely than white people to suffer from kidney failure



Base: All respondents (I = 306, P = 306, B = 332 and BC = 351)

Cultural and religious barriers

To better understand any lack of awareness or resistance to organ donation, the research investigated cultural or religious issues that might act as barriers for black and South Asian people.

While 32% said they had never thought about joining the ODR, 21% of people stated that their religion did not allow it. This was particularly important to Pakistani (22%) and Bangladeshi (43%) people. 10% of people cited burial and funeral customs as a barrier to joining the register.

For Indians there was the need for close family members to wash the body of the dead relative and cremate the body and Muslims needed to bury their loved ones quickly after their death.

Other reasons cited were:

- fear of death – 13% of people were superstitious about death and concerned that, by talking about death, this could become a reality
- mistrust of the medical profession – some respondents felt that registering as a donor or carrying the card would mean that not everything would be done to save their lives in the event of a serious illness or accident
- some black people held a fatalistic view that it was in the hands of God to decide who lives or dies, and it was not up to people to intervene by donating organs.

Despite these barriers, both black and South Asian people stated that they agreed that it was important to help their community and "put something back". Also many Asians and the more religious black people felt that "doing good", helping others and serving their community was a fundamental part of their religious faith. In fact "doing something for your community" was a means of fulfilling aspects of Islam, Hinduism and Sikhism which dictated "doing wider good". Given that many respondents had initial misconceptions that their faith prohibited organ donation, this is an attractive counter argument for donation.

Also a perceived status within society appears to have an impact on attitudes, particularly amongst some black people. They feel marginalised by mainstream society and this affects their willingness to participate in initiatives seen to come from mainstream organisations.

Getting the message across

67% of people interviewed said that it was very important to have specific organ donation campaigns targeted at black and South Asian people to get the message across properly.

Overall, 20% of people had recently seen specific media coverage about organ donation targeted at black and South Asian people. Of these black people had the highest recall of coverage (29%).

Not surprisingly, UK Transplant's black and South Asian leaflets were popular with interviewees. The South Asian leaflet *What does your future hold?* was popular with 48% of people because it featured many nationalities. The black leaflet (featuring comedian Curtis Walker) was praised for being bold, hard-hitting and eye-catching and was the favourite leaflet for black people.

The interviewees suggested ways that communication materials could be modified to make them even more relevant to each community.

For South Asians this included using religious messages, more South Asian case studies of people whose lives have been saved and those still suffering because of a lack of donors, and using South Asian celebrities and role models to endorse organ donation.

They also suggested distributing materials to doctors' surgeries as well as community centres and places of worship, and reaching younger Asians via Freshers' Fairs, student pigeonholes and NUS student packs. (UK Transplant provided all UK surgeries with materials in spring 2006 and targets Freshers' Fairs with significant numbers of ethnic students each year).

Black interviewees suggested continuing to use Curtis Walker, who is a powerful advocate, encouraging other black celebrities to support the campaign, and using case studies. They wanted to see materials available in local outlets such as nail bars, hairdressers and shops as well as health surgeries and youth and community centres. (UK Transplant distributed materials to these outlets in areas with high black populations in spring 2005).

What does the research show us?

Overall, the research shows that the campaign work already done by UK Transplant is relevant to black and South Asian people. The targeted materials are appropriate and they are already being distributed to the right outlets. However, there continues to be a need to generate discussion at grass roots level if attitudes are to be changed. Young and older people need separate approaches (eg via universities and schools for young people, via community centres and places of worship for older people) backed up by targeted distribution of leaflets. Using ethnic television and radio will also help reach greater numbers of people.

Angie Burton, UKT's Marketing and Campaigns Manager said, “The research is encouraging since it shows that we are already taking the right approach to inform black and South Asian people about organ donation and transplantation. In light of the research we will be revising our targeted materials later this year to give them a wider appeal.

“It is obvious, however, that there is no 'quick win' to increasing the number of black and South Asian people willing to be organ donors. To be effective we need to take a long-term view and find ways of encouraging debate within families and within communities.

“Our challenge is to do this within the context of limited resources. We need to build on the work that we've done and continue campaigning to persuade black and Asian people that organ donation is an issue that is relevant to them.”

British Transplantation Society presentations

At the British Transplantation Society annual conference, held on 29-31 March in Edinburgh, UKT’s Statistics and Audit Directorate presented several papers. These covered a wide variety of analyses including aspects of solid organ and cornea donation and transplantation. Four of the presentations are summarised here.

The potential for paired living kidney donation in the UK

ABO incompatibility and the presence of donor-specific HLA antibody preclude many potential living donor kidney transplants. From September 2006, the Human Tissue Act will enable paired donation in the UK, whereby incompatible donor-recipient pairs can exchange kidneys so that recipients can receive alternative compatible living donor organs (see Figure 1).

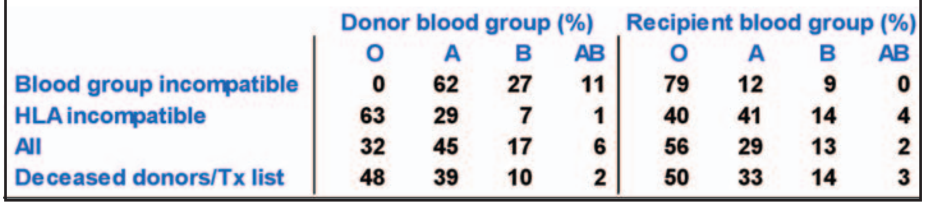
All transplant centres in the UK were contacted in Autumn 2005 and asked to provide data from the last two years on living donor kidney transplants that could not proceed because of blood group or HLA incompatibility. The purpose of this was to establish the potential for a national paired kidney donation scheme in the UK, and to facilitate computer simulations to determine how such a scheme would be most effective in practice.

Data were received from 20 (of 24) UK transplant centres relating to 411 potential recipients associated with 539 possible donors – 22% of patients had more than one prospective (incompatible) donor. 46% of the potential donor-recipient pairs were blood group incompatible and 54% were HLA incompatible (positive crossmatch).

The demographics of the potential recipients and their prospective donors were very similar – mean age was 43 years, and approximately 50% were male and 87% were white. The most common donor-recipient relationships were spouse or partner (28%), sibling (26%) and parent (17%). At the time of data collection, 66% of the potential recipients were still on the deceased donor transplant list, while 11% had received a deceased donor transplant and a further 3% had received an alternative living donor transplant.

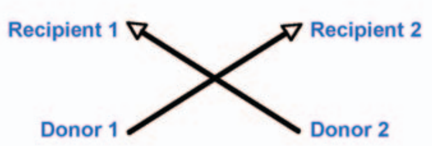
Blood group distributions of the potential recipients and their donors are different from those in normal donor and recipient pools, as shown in Table 1,

Figure 1 – Paired donation - an exchange of kidneys



	Donor blood group (%)				Recipient blood group (%)			
	O	A	B	AB	O	A	B	AB
Blood group incompatible	0	62	27	11	79	12	9	0
HLA incompatible	63	29	7	1	40	41	14	4
All	32	45	17	6	56	29	13	2
Deceased donors/Tx list	48	39	10	2	50	33	14	3

Table 1 – Blood group distributions



and suggest that too few blood group O donors will be available to meet demand.

To inform discussion on the complex issues surrounding the establishment of a national paired kidney donation scheme, the data collected will be used in computer simulation models developed to compare and contrast the effectiveness of alternative matching algorithms.

A joint BTS/UKT working party chaired by Dr Chas Newstead is set to make recommendations about how both altruistic non-directed and paired/pooled donation should be taken forward in the UK.

Other members of the working party are: Laura Buist, Lisa Burnapp, Phil Dyer, Paul Lear, Phil Mason, Sue Fuggle, Rachel Johnson and Joanne Blackwell.

Hepatitis C virus and liver transplantation

Hepatitis C is a common indication for liver transplantation and inevitably recurs in the graft post-transplant. This study assessed long-term survival following liver transplantation for patients infected with hepatitis C virus (HCV-pos), compared to those without HCV infection (HCV-neg). The influence of donor, recipient and transplant factors on post-transplant survival was also investigated.

Data on 3,648 first adult elective heartbeating liver-only transplants in the UK (1994-2005) were analysed. Patients with unknown HCV status or with concurrent hepatitis B virus or liver cancer were excluded.

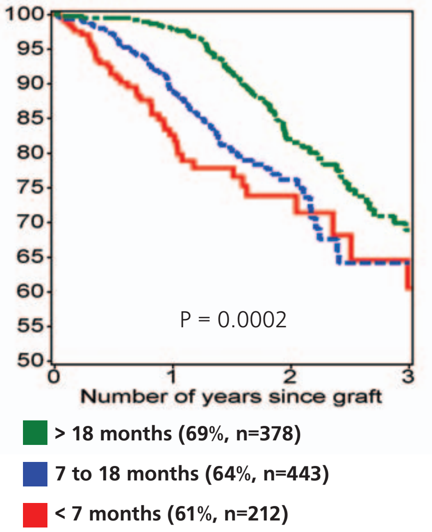
Eight-year graft survival for HCV-pos patients was significantly inferior to that for HCV-neg patients: 47% (95% CI 40-54) and 64% (95% CI 62-67), respectively. A similar difference was observed for patient survival: 55% (95% CI 47-61) for HCV-pos patients and 70% (95% CI 67-72) for HCV-neg patients.

In multivariate analysis, recipient age and transplant year were found to significantly influence graft survival for HCV-pos patients. Although these factors were not significant for HCV-neg patients, the trend was similar for both groups. After adjusting for all relevant risk factors, the overall relative risk of transplant failure for patients with hepatitis C, compared to those without hepatitis C, was 1.28 (95% CI 1.09-1.50).

Outcomes of penetrating keratoplasty in patients with pseudophakic bullous keratopathy

Pseudophakic bullous keratopathy (PBK) is one of the main indications for corneal grafting and accounts for about 18% of first corneal grafts in the United Kingdom. However, the graft survival for this group of patients is poorer than the other main indications. 65% of first grafts for PBK were still surviving at three years, whereas the graft survival rates for the other main indications (Keratoconus and Fuchs' dystrophy) were much higher at 96% and 92% respectively.

Figure 2 – Comparison of graft survival at three years by length of time on steroids



There are a number of reasons for poor graft survival among patients requiring a corneal graft for PBK, including incidence of glaucoma and vascularisation.
The eyes may also be immunologically primed due to repeated episodes of ocular surface breakdown and inflammation, and the aim of this study was to determine whether the length of time on steroids affects graft survival.

Referring to Figure 2, patients receiving steroids for longer than 18 months had better graft survival than those on steroids for less than this, and the grafts were half as likely to fail when taking account of other factors affecting graft survival.

As a result of these findings ophthalmic units may want to consider whether all grafts for PBK should be maintained on long-term steroids. This research is being submitted to the British Journal of Ophthalmology and will be presented at the next OTAG meeting.

Does transplantation improve survival for established renal failure patients in the UK?

Continuing increases in survival rates for patients on dialysis, and also in patient survival following transplantation, mean that it is important to have an up-to-date picture of the advantage of transplantation in patients registered for transplantation.

Collaboration between UKT, the UK Renal Registry and the British Transplantation Society has led to the first UK-wide study of such patients, in which the risk of death following a kidney transplant was compared with that of remaining on the transplant list.

The analysis was based on 10,537 adults listed for a first-kidney-only-transplant between 1995 and 2000. Of these, 65% received a deceased donor transplant and 8% a living donor transplant.

The results showed that following a deceased donor transplant, there was a four-fold increase in risk of death immediately after the transplant, but that after five months there is an increasing survival benefit of transplantation. The advantage of transplantation is seen earlier in recipients of live donor transplants.

...Robert Bonser

Robert Stuart Bonser MD, FRCP, FRCS, FESC is the recently elected Chairman of the Cardiothoracic Advisory Group. He is a consultant cardiac surgeon and Director of the Heart Lung Transplant Unit at the University Hospital NHS Trust, Birmingham.

Qualifying in 1997, he has undergone surgical training in the West Midlands and cardiac surgical training in the West Midlands and London. In 1987-8 he undertook a fellowship in heart and lung transplantation at the University of Minnesota. He is married with one daughter.

Q What prompted you to specialise in cardiothoracic transplantation?
A Unlike other solid organ transplant disciplines, in cardiac surgery, transplantation represents only a part of the operative workload. My own interests include standard cardiac surgery and additionally thoracic aortic surgery.

My transplant interest arose following the introduction of Cyclosporin A and the introduction of heart lung transplantation in the early 1980s. Although it was my intention to take a career in cardiac surgery, I preceded this with training in renal and liver transplantation with Anthony Barnes and Paul McMaster. This galvanised my interest in transplantation when I entered cardiac surgery in 1984.

Q What else might you have done?
A Although I had a science based education I would have dearly liked to have been a historian. Historical research to try and unravel a story from the past is much like the preparation for clinical research studies.

I had occasion to consider alternative career options some years ago when I was informed that I was Hepatitis B positive. This was shown to be a false positive result 24 hours later but in the interim I decided that I would move to basic clinical science, probably physiology, so that I would not be constantly reminded of my first career choice.

Q What aspect of your current role gives you most satisfaction?
A Undoubtedly, this relates to the urgent heart transplant scheme and seeing young critically ill patients, transformed by heart transplantation. This has to be the area in which cardiothoracic transplantation plays its most demonstrable role.

Q What aspect do you least enjoy?
A There are two. The first is the disappointment of seeing transplant recipients succumb from allograft vasculopathy after 5-15 years. Many cannot be considered for re-transplantation because of the progressive organ damage due to immunosuppression. If we can prolong graft viability this would be a major step forward.

The second relates to the administrative headaches and paper exercises that now govern all of our lives. Although inevitable, there is no doubt that this will frustrate development and innovation.

Q What has been the greatest success so far in your career?
A Achieving the goals of professional development such as diplomas, degrees and grant awards are obviously satisfying. I don't think I have any great successes just a series of minor ones that cumulatively give some satisfaction.

All the peripheral successes have to be judged against the satisfaction drawn from seeing patients come through major surgery and transplantation and being restored to health.

My most memorable moment was my first heart transplant in the UK.

Q What one piece of advice would you give to someone new to cardiothoracic transplantation?
A Despite the current work-time based contract, there is no substitute for experience. If you are interested you will read about the subject and become engaged in all aspects of transplantation within your unit.

You will have to come to terms with the anti-social nature of transplantation and learn by experience night after night, regardless of on-call rotas, until you are experienced enough to take a lead role.

Q What has been the most radical change since you have been involved with the transplant community?
A Change is rarely radical or rapid. The instigation of a zonal retrieval system was undoubtedly a major step-forward for cardiothoracic transplantation and its role has been validated by prospective outcome assessment.

The urgent heart allocation scheme has most definitely been a change that has saved lives and its continued use and audit are welcomed. The advent of non-heartbeating donation offers great promise particularly for lung transplantation.

The long-term use of left ventricular assist devices as a substitute for transplantation has yet to yield its true contribution. Undoubtedly as LVADs are refined and costs reduced, this will produce a radical change in the care of heart failure patients.

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

A I would consider reviewing the system of positive incentives for intensive care units to identify potential donors to try and ensure that as many transplant procedures as possible can be performed. I would provide funding to augment donor care so that identified donors can be optimised and resuscitated to ensure that we make the best use of the current donor pool. I would improve incentives and training opportunities for surgeons interested in transplantation to improve recruitment into a somewhat unpopular aspect of the speciality.

I would initiate a required potential donor identification scheme for ITUs that contributed to "star" ratings.

I would initiate an educational school-based programme so that the population is drawn towards a culture of organ donation and initiate a research grant to examine what concerns lead to refusal for donation.

I would reconsider the arguments for required requesting.

Q How do you relax?

A Sleeping with the phone turned off, skiing in the winter, golf (once or twice a year), walking, reading and just being at home with my family.

ADVISORY GROUPS

Ocular Tissue Advisory Group

OTAG met on 25 January 2006

- Work is underway to record the splitting of limbal stem cells and other types of splits on the UKT database. The tissue information sheets that accompany all corneas and sclera will be amended to indicate the risk of transmission of diseases that cannot yet be tested for, including vCJD and sporadic CJD.
- Work is underway to establish an allocation procedure for automated lamellar therapeutic keratoplasty (ALTK) grafts similar to that for paediatric corneal grafts.
- The Department of Health will be clarifying whether whole donor eyes can be used before the result of an HTLV test is available due to the clinical need to use these eyes quickly. Every effort will be made to minimise the number of these cases and patients will be made aware of the risk versus benefit of the procedure.
- A pilot testing facility has been established for screening tissue donors for vCJD using donor tonsillar tissue. Only ocular tissue from CTS eye banks is tested, as the results need to be recorded on the UKT database.
- Any research carried out from UKT data should include the statement "on behalf of UK Transplant Ocular Tissue Advisory Group and contributing ophthalmologists" on the authorship line. Data will be released for those projects that have been approved by the audit and analysis sub-group of OTAG.
- The NBS *Tissue Donor Selection Guidelines* have been updated and cadaveric guidelines relevant to ocular tissue are now included. The guidelines are available on the NBS website. These are in addition to the contra-indications on the Royal College of Opthalmologists' website.
- Seventeen per cent of donated corneas tested at the Bristol Eye Bank between May and November 2005 were rejected due to repeat reactive results for Human T cell Lymphotropic Virus (HTLV). This is far higher than the incidence of HTLV in the population and the Chair of OTAG has written to the Committee for the Microbiological Safety of Blood, Tissues and Organs (MSBTO) regarding this issue and the lack of validity of these tests for cadaveric donors.
- Further improvement has been made in the return rates for the transplant record form and the one and two-year follow-up forms. However, the return rate for the new five-year follow-up form is considerably lower.
- A proposal for amending cornea requests once they have been made was approved. This allows the Duty Office at UK Transplant to track donor material more efficiently. The new process will be implemented in early May 2006.
- The first technical EU tissue directive will be implemented in Autumn 2006. The second directive is unlikely to be implemented until Autumn 2007 therefore work is underway to establish an interim system for adverse event reporting. The Human Tissue Authority (HTA) has agreed a form of interim licensing which came into effect on 7 April 2006 whereby anyone storing cells or tissue for therapeutic use will have to apply for a licence from the HTA.

Cardiothoracic Advisory Group

CTAG met on 1 March 2006

- Work is underway to develop a consensus model for donor management in cardiothoracic centres. The current provision for donor management will be reviewed, including the donor care physiologist scheme at Papworth, and the work undertaken in Birmingham on early medical management.
- New forms for living donor lung transplantation are to be implemented in due course.
- The MSBTO guidelines published in 2000 are due to be revised during 2006. MSBTO has reported that potential donors who have received blood transfusions in the past are to be excluded from donating bone, muscle or

tendon to minimise the risk of vCJD. There is currently no expectation that they will be excluded from donating ocular tissue or solid organs.

- From 1 April 2006 the Royal College of Surgeons Clinical Effectiveness Unit and UK Transplant have joint responsibility for the clinical audit of UK cardiothoracic transplant services.
- An experimental study to demonstrate the feasibility of non-heartbeating heart donation will be performed initially on a large animal model under the direction of the non-heartbeating heart donation project team.
- Investigations have taken place into the feasibility of finding a cross-match negative donor for cardiothoracic patients who are sensitised to HLA antigens. Further analyses will take place to develop an appropriate mechanism to overcome the difficulties of transplanting these patients.
- The current system of urgent heart allocation disadvantages patients awaiting a heart/lung transplant. UKT will assess the number of cardiothoracic donors where the heart was not used due to size and investigate the feasibility of developing a mechanism of primacy for a heart/lung block in those instances where only the lungs would be used, as the heart is too small.
- The offering rules for blood group 'O' donor hearts should also apply to paediatric patients to ensure that blood group 'O' patients are not disadvantaged. These offers must be preferentially considered for 'O' and 'B' blood group patients at all centres before being considered for 'A' and 'AB'.
- A study to identify suitable heart donors using biochemical probes is being developed.
- All centres should be able to receive faxed fast-track offers 24-hours a day as it is inappropriate for centres to receive verbal offers. Previously verbal offers have resulted in delays to the offering sequence so a decision has been made that verbal offers will no longer be made.
- As part of the contract between the Republic of Ireland and Newcastle, five lung transplants have now been performed in Ireland together with the long-term care of those Irish patients transplanted in Newcastle. There are currently 30 patients on the Newcastle lung transplant waiting list from Ireland and the contract is likely to continue for the foreseeable future.
- Newcastle is the only centre in the UK performing lung transplants from non-heartbeating donors. Harefield is now ready to consider local offers of these organs and therefore should have first refusal for offers within the local area. If Harefield does not accept then the organ will be offered to Newcastle. Lungs from non-heartbeating donors from all other zones will be routinely offered to Newcastle first until such time as those centres developing programmes inform the UKT Duty Office that they are ready to consider local offers.
- A working party is being established, including representation from the Paediatric Intensive Care Society, to consider the numbers of paediatric donors and to develop a protocol for their identification and management.

Donation Advisory Group

DAG met on 27 March 2006

- The proposed terms of reference and membership arrangements for this new advisory group were endorsed. Comments were requested on the proposal that Dr Martin Smith should chair the group.
- Further analysis will be carried out on the Potential Donor Audit (PDA) to assess the ethnicity of families not approached about donation.
- Regional differences between coroner refusal rates will be raised with the Department of Constitutional Affairs, which has responsibility for the coroner services, and through them to the Coroners' Association. In addition, guidelines previously drawn up for coroners relating to working with the transplant community will be circulated to members.
- A simulated intensive care environment to train ICU nursing staff is being piloted at the Cheshire & Merseyside Simulation Centre based at University Hospital Aintree. A sub-group of DAG will be formed to assist UKT Statistics & Audit Directorate to ensure appropriate revisions are made to the PDA forms in order to enhance analysis of the data.
- In order to minimise the workload of co-ordinators who complete PDA forms, from April 2006 deaths in cardiothoracic units and cancer units will not be audited due to the low potential for donation. In addition, deaths of potential donors aged 75 and over will not be audited although referrals will still be provided.
- The Intensive Care Society (ICS) is to be approached to recommend brain stem death testing for all potential donors.
- A working group was established by UKT to compile guidelines on donor management, which have now been superseded by the ICS guidelines for adult organ and tissue donation, which were endorsed by DAG. Each ICU needs to develop their own local protocols based on these guidelines. A working group is being established to define paediatric donor management guidelines.
- Only a limited number of units are progressing non-heartbeating donors. The definition of futility needs to be addressed and stringent guidelines produced on withdrawing treatment within emergency medicine departments. Draft recommendations will be produced for consideration at the next meeting.
- Clarification is to be sought from the Academy of Medical Royal Colleges' working group on the acceptable levels of

phenytoin, opiates and thiopentone in patients on whom brain stem death testing is to be carried out.

- Following the review of the donor liaison scheme last year the donor liaison nurse element of the scheme was withdrawn due to the lack of any increase in solid organ donation from the scheme. The role of donor liaison clinicians was therefore also brought to an end. Any future clinical advice required by UKT will be sought from DAG.

Pancreas Task Force

PTF met on 7 April 2006

- Work is ongoing on the proposed pilot schemes to increase access to pancreas transplantation of sensitised patients by the sharing of organs between Oxford and Cambridge and between Edinburgh and Newcastle. The centres involved will be awarded the appropriate debit/credit within the balance of exchange for the import/export to the other centre. In the event of a pancreas being transferred from one centre to the other and the potential recipient becoming unwell then the organ should remain at that centre for transplanting into another recipient rather than being returned to the original centre or entering the national sharing scheme. The frequency of these occurrences will be monitored. The definition of a sensitised patient is a patient who has a positive cross-match with 30% of donors. Guidance will be produced for centres on the most accurate method of defining a sensitised patient so that they can be notified to the UKT Duty Office. In addition, the recommendation that a 30% HLA antibody reaction frequency be used as a uniform definition of sensitisation for dual registered sensitised patients was endorsed.
- All forms relating to donation will be amended due to the change in consent processes under the new legal framework. An agreed core of information will be mandatory with the remainder dependent upon individual circumstances.
- The National Transplant Database does not currently enable patients to be listed simultaneously at two different centres although future developments should facilitate dual registrations at two different transplant centres. Non-sensitised patients should be listed for either a kidney-only or a pancreas/kidney transplant and only sensitised patients should have the choice of dual registration. UKT will review the sensitisation information on all patients known to be dual registered and propose a formal process for dual registration.
- Future work will take place on factors influencing pancreas survival in order to develop a risk adjusted model for pancreas survival.
- There is no statistical evidence to suggest that kidney graft survival or patient survival for simultaneous pancreas/kidney and kidney-only transplants differ in the treatment of diabetic patients. There is evidence to show that kidney graft survival is slightly higher in simultaneous pancreas/kidney transplants although this is largely explained by the use of kidneys from younger donors. Future work will include the examination of outcomes for kidney-only recipients from living donors in diabetic patients.
- A proposal was endorsed to enable the prompt referral of a pancreas from a donor where the designated retrieval team cannot retrieve the organ so that an alternative retrieval team can accept it. Where more than one centre expresses an interest the priority is given on the balance of exchange and neither the designated retrieval centre nor the alternative retrieval centre will be credited or debited with export/import points. Following the rapid referral offer to all centres, if none accept after 60 minutes the Duty Office will routinely contact those centres that have not responded to ascertain the reasons for the lack of response. The pancreas will not then be offered again through the normal offering sequence. In addition, there was an undertaking to review the current zones in order to align them with retrievals. The start date for the scheme will be advised in due course.
- It is not the responsibility of the UKT Duty Office to decide whether a pancreas is transplantable and the Duty Office will carry on offering in the correct sequence. If an individual centre states that they don't want the offer of a pancreas once a certain time is reached, or after it has been refused by a given number of centres, then that request can be registered.
- The majority of centres are retrieving over 90% of the pancreata in their zone. Further adjustments might be required to make the zones more evenly balanced but it is too early, after only 12 months, to consider making any changes.
- It has been proposed to the Chairman of the Liver Advisory Group that where there is an anomalous liver blood supply such that a replaced right or accessory right hepatic artery from the superior mesenteric artery gives branches to, or travels within, the pancreas then the artery should be divided as it passes lateral to the duodenum.
- Pancreas centres should review their arrangements for receiving fast-track offers and ensure there is a robust system in place out-of-hours to receive these offers.
- The decision on whether to accept offers of pancreata for sensitised patients should be made in consultation with the tissue typing laboratory due to the complexity of the HLA typing nomenclature. An appropriate matching run can be performed for centres where all patients are registered only for a combined kidney/pancreas transplant. It cannot be carried out at present where patients are registered for a kidney-only transplant at another centre.

Nurse wins award for living kidney research

Paul Gill receiving his Marjorie Simpson New Researchers award.

Paul Gill, a final year PhD student from the University of Cardiff has won the Marjorie Simpson New Researchers Award, one of the top awards for nursing research. Paul is studying at the School of Nursing and Midwifery and his final thesis will be submitted in June 2006.

Paul investigated the decision-making process for living kidney donors and their recipients, an area which has been subject to very little research. His study highlights how, in contrast to the decision-making process for donors, which tends to be instant, voluntary and relatively easy, recipients find accepting a transplant very difficult because of their concern for the donor's well-being.

Paul recruited living kidney donors and their recipients who had been transplanted at Southmead Hospital in Bristol. All were interviewed pre-transplant, and twice in the first year after transplant.

The research develops the idea of "the joy of giving" and the emotional reciprocation that donors receive when they see recipients' lives transformed. The research also provides an insight into the experience of graft rejection, which appears to be akin to bereavement.

On receiving the award, Paul said: "I hope that my research will provide some insight into the living kidney transplantation process that could be used to improve understanding and help inform and develop future clinical practice in the field."

A group of medical students from Birmingham University have carried out a **study to look at how attitudes towards organ donation differ between blood and non-blood donors,** as well as between different ethnic groups, age groups, and socio-economic groups.

They interviewed 170 participants in the Birmingham area, at three different sites (New Street, Redditch and Kings Heath). At each site blood donors at the local blood donation centre/session were interviewed, and non-blood donors in the corresponding high street.

The findings showed that blood donors were more likely to agree with organ donation in principle, and more willing to donate their organs in the future than non-blood donors. Blood donors were also more aware of how to join the NHS Organ Donor Register and were more likely to carry an organ donor card than non-blood donors.

Although Indian and Pakistani participants agreed with the concept of organ donation, they were much less willing to donate their organs in the future.

People under 20 were the least knowledgeable about organ donation, as were participants from ethnic minorities and lower socio-economic groups.

Blood donors were more likely to have discussed their decision to donate organs with their next of kin, than non-blood donors, as were people of higher socio-economic groups. The study was carried out by K Baker, D Duke, C White, L White and D Wilson.

A group of keen **runners from Cosford, have been sporting the "Signed Up Yet" logo** on specially designed T-shirts in a bid to promote organ donation. Supported by the Defence College of Aero-Nautical Engineering, John McGlasson (pictured below centre) and friends started out by running to raise money for the Shropshire and Mid-Wales Kidney Patients' Association to enable them to buy a new dialysis machine.

The team enjoyed the run so much that they decided to continue, but instead of raising money they chose to promote the NHS Organ Donor Register. John's 19-year-old daughter is on the waiting list for a kidney after her last transplant rejected, so John and his colleagues are determined in their efforts to raise awareness.

The **Donor Family Network are organising a Gift of Life multi-faith service,** where representatives from Christian, Muslim, Hindu and Jewish faiths will be present. Members of organ donor families, transplant recipients and hospital staff will address the service, taking place 16 July 2006 in Bolton. For more information contact John Buckley of the Donor Family Network, tel: 01942 870685.