

bulletin



NHS

UK Transplant

The newsletter for everyone involved in organ transplantation and donation
Issue 55 Summer 2005

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In a few months UK Transplant will be abolished and on 1 October its functions and responsibilities passed to a new authority - NHS Blood and Transplant (NHSBT). As many of you will now know, as a consequence of being appointed to an acute Trust Chief Executive post, I will no longer be a candidate for the Chief Executive of NHSBT and therefore this is an opportunity for me to reflect on what has been achieved in the last four years, consider the challenges for the new leaders of NHSBT and thank you for your hard work and support.



By working together we have achieved a lot. We have successfully raised the profile and importance of donation and transplantation and have reversed the decline in organ donation, increasing transplantation rates for the first time in five years.

The expert advisory groups are producing superb advice and the impetus for the continuing modernisation and improvement of services. We have a cohesive team of expert and professional donor transplant co-ordinators and a fantastic team of people based at UKT who lead on national campaigning, working closely with colleagues in the charitable and other sectors, who match and allocate organs, provide crucial IT and data collection support services to ensure the safety of patients and produce robust statistical evidence on which to base improvements in patient care.

The statutory instruments setting out the high-level function and constitution of NHSBT will shortly be submitted to the Welsh Assembly and Parliament for approval. In Scotland and Northern Ireland arrangements are underway to ensure that NHSBT has cross-border authority status.

A stakeholder advisory group has been established to include a wide range of representatives. They will provide advice to NHSBT's new Chairman on arrangements for strategic direction, organisational

outcomes and formal professional advisory group arrangements that will be required to deliver the ongoing challenges, which include:

- continuing to increase the availability of organs for transplant
- maximising patient safety and patient and graft survival
- providing authoritative, independent, relevant and accessible information about donation and transplantation and the opportunities for improvement
- engaging the general public in the importance of donation by campaigning comprehensively
- providing leadership for the UK's transplantation service
- improving patient and family experience by providing a seamless organ and tissue donation service
- supporting the staff of the organisation to create an efficient, flexible and highly skilled organisation
- delivering world-class blood, tissue and transplantation services.

In the meantime it is very much business as usual. Confidence in UKT was demonstrated by approval and funding of this year's Business Plan and this has enabled us to extend the service level agreements for non-heartbeating and live donor programmes until 2008. In addition discussions are underway about converting the investment in donor liaison programmes to in house donor transplant co-ordinators.

Thank you for your support over the last four years. It has been great fun working with you all and I have every confidence that, with your ongoing commitment and energy, transplant services will continue to prosper in the future.

Sue Sutherland
Chief Executive
UK Transplant

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*Front cover picture:
Comedian Curtis Walker and
salon manager Chester
Julien supporting the black
campaign. See page12.*

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

Chair of NHS Blood and Transplant appointed



Bill Fullagar: Chair of the new NHS Blood and Transplant.

The former President and Chief Executive of Novartis, E J (Bill) Fullagar has been appointed chair of the new NHS Blood and Transplant (NHSBT).

Mr Fullagar will oversee the implementation of NHSBT, which will be established on 1 October 2005. He will work three days a week. He said: "I am delighted to be appointed as the designate Chair of NHS Blood and Transplant. I look forward to the role immensely, and to working with the blood and transplant

community in the delivery of a world class service."

Mr Fullagar, who is 66 and lives in Woking, Surrey, has had a distinguished career and wide experience at director/chairman level in the industrial pharmaceutical field. His positions have included President and CEO of Novartis Pharmaceuticals UK Ltd. From 2001-2003 he was President of the Association of the British Pharmaceutical Industry.

Health Minister, Rosie Winterton, said: "I am delighted at the appointment of Bill Fullagar and look forward to working with him. NHSBT will build on the excellent service and reputations of the National Blood Authority and UK Transplant. I am confident that Mr Fullagar's leadership skills and expertise will help NHSBT in its role of promoting the importance of blood, tissue and organ donation and helping to improve and save people's lives."

Welsh Health Minister, Dr Brian Gibbons, added: "The Welsh Assembly Government welcome Mr Fullagar's appointment as the first step in giving life to this new organisation which will play such a significant role in the provision of blood and transplant services."

NHSBT is a new organisation being established as part of the review of Department of Health's arms length bodies. It is being created from the merger of UK Transplant and the National Blood Authority.

The objective of the merger is to increase the supply of donated blood, organs and tissue and raise the quality, effectiveness and efficiency of blood and transplant services.

NHS Blood and Transplant will be a Special Health Authority. It will replace the National Blood Authority and UK Transplant from 1 October 2005.

Living transplants reach all time high

UK Transplant's end-of-year figures show that more than one in four of all kidney transplants in the UK now rely on the generosity of a living donor.

A total of 1,783 patients received a kidney transplant last year (2004-05) of which 475 (27%) were given their kidney by a friend or relative – the highest number of living kidney transplants ever recorded in the UK. The figures also include a record number of kidney transplants from non-heartbeating donors – 143, 20% up on the previous year. These are patients who died in hospital but were not on a ventilator.

Sue Sutherland, UKT's Chief Executive, said the figures justified UKT's strategy of investing almost £10m over the past four years into hospital-based donation programmes.

"These results show the importance of investing in these new programmes and the real value of extending such programmes, which are currently operating in just 48 trusts, across all suitable NHS trusts.

"The living donor programmes alone have generated a 40% increase in living kidney transplants when compared with 2000-2001."

In addition during 2004-05:

- 2,375 people had their sight restored by a cornea transplant – the highest number for eight years
- a million more people pledged to help others after their death by registering their wishes on the NHS Organ Donor Register
- 86 people received a pancreas or combined kidney / pancreas transplant – the highest number on record.

The number of people who donated organs after their death dropped by 22 to 750 last year, reducing the overall number of organ transplants by 5%.

Sue added: "Transplant success rates are constantly improving with 85% of heart transplants; 87% of liver transplants; 93% of living kidney grafts and 88% of transplants using kidneys donated after death surviving the critical first year."

BBC focus on organ donation

The BBC is planning to broadcast a major season of programmes highlighting issues around organ donation in the UK at the end of August.

BBC One will screen five half-hour documentaries and a Casualty/Holby City special, where, for the first time, viewers will be invited to vote by phone to decide the outcome of the organ donation storyline.

Transplant co-ordinators and clinicians in a number of centres are closely involved in the making of the five documentaries, Life On The List, which will tell personal stories about organ donation and transplantation. Already more than 100 hours of film have been captured, ready for editing, and filming is still continuing.

There will also be a one-hour documentary showing a kidney transplant from a live donor, but at the time of going to press, it had not been decided which transplant centre would feature in this programme.

Smart move by Southampton

Southampton City Council is the first local authority to promote organ donation through its Smartcities scheme. Smartcities is a multifunction card that allows people to access a range of local services – including libraries, leisure facilities and bus travel – with just one card.

As part of the Southampton scheme, anyone applying for the smartcard (via a paper form) will be given the opportunity to join the register. The information provided will be electronically downloaded to UK Transplant.

The Southampton scheme is due to be launched in July and the council is keen to promote its organ donation scheme as a template for other local authorities developing their own smartcard schemes.

If your council would be interested in learning more about this initiative email: campaigns@uktransplant.nhs.uk

The Casualty/Holby City special will include a factual break featuring interviews with transplant and intensive care experts explaining key scenes from the drama, in detail.

This special season, called “DoNation” was commissioned by BBC Learning and BBC One and aims to “raise awareness, explain the facts, dispel myths and encourage people to make an informed decision about whether to add their name to the NHS Organ Donor Register”.

The season will feature broadcasts on national and regional radio including Radio 1, Radio 2, Asian Network and 1Xtra.

There will also be opportunities to join the ODR built into the season including a dedicated website on www.bbc.co.uk/donation. Digital viewers will also be able to use their red button to register – an innovative development for the red button facility.

DoNation will be extensively promoted on the BBC – check your TV guide for dates and times of programmes.

Life-saving liver operation pilot

The transplant unit at St James’ Hospital is set to launch a pilot programme for children with liver disease to be treated through live transplantation.

The Leeds pilot, pending final approval by the Department of Health, will involve a close relative of the young patient donating part of their own liver, rather than the child waiting for a cadaveric donor.

The living related liver transplantation is currently only performed in the UK at King’s College Hospital. Around 90 paediatric liver transplants are performed each year. Half involve children under two years old and there is a shortage of size-matched donor organs for these children.

Coming to a local cinema soon

Recent discussions with publishing house Concept Publishing have resulted in a fantastic gesture of support for organ donation. Full page advertisements with registration forms will be appearing in cinema magazines right across the UK.

The Odeon, Vue (Warner Village), Cineworld and Showcase magazines will be carrying an amazing 1.5 million advertisements free of charge to encourage more people to join the NHS Organ Donor Register.

Paul Constant, Media Sales Executive for Concept Publishing said, “We wanted to give maximum coverage to help promote this significant cause”.

Why do families say no?

Researchers at Southampton University are embarking on a major national study, funded by UK Transplant, into bereaved families' attitudes to organ donation, their decision-making and hospital experiences.

The study has been commissioned as part of a series of measures UK Transplant is taking to address the relative refusal rate, which at 42% is higher than studies showed in the late 1980s/early 1990s (30% refusal rate). Other measures include best practice training programmes, and requiring all personnel involved in the organ donation process to access the NHS Organ Donor Register on every occasion a potential donor is identified, to establish whether the individual had registered their wishes.

The study team is led by Dr Magi Sque, Senior Lecturer in Southampton University's School of Nursing and Midwifery. The team is using a radio and newspaper campaign, as well as three NHS Trusts, to reach bereaved family members from across the UK, who chose not to donate organs or tissue of a deceased relative for transplantation, after being approached about donation.

"If people in the transplant or intensive care fields also know of anyone who would wish to take part, they would be welcome to pass on our details to those family members," said Dr Sque.

Relatively little is known about the experiences of relatives who do not donate. Dr Sque says the issues they hope to investigate include:

- the special care that may be required by relatives at the time of death, at the discussion about organ donation, and over the months that follow
- the impact of hospital care and



The study team is led by Dr Magi Sque.

- bereavement on a family's life
- the good and bad points of hospital care when talking about donation and possible choices
- whether hospital staff respected religious and other beliefs
- what support was offered during and after the hospital stay, including the availability of bereavement counselling.

To find out more about the new study, see the website: www.nursingandmidwifery.soton.ac.uk/familybereavement or contact Research Fellow Diana Allardyce on 023 8059 8231, and on d.allardyce@soton.ac.uk.

The results of the study will be available at the end of 2005.

Two years ago, Dr Sque and her team published a report following a three-year investigation into the experiences of bereaved adults who chose to donate. That study was commissioned by the British Organ Donor Society (BODY) and involved 46 family members who donated their deceased relative's organs and three who declined donation.

New president for BTS

The new President of the British Transplantation Society is John Forsythe, Consultant Transplant Surgeon at Edinburgh Royal Infirmary.

John took up his two year appointment in April: "I have been closely involved with the BTS for many years, first as General Secretary, Vice President and now President. It is a vibrant organisation with strong input from all elements of the multi-disciplinary team which looks after transplant patients.

"Important initiatives at present include the review of each constituency which makes up the Society, consideration of peer review visits to centres in collaboration with UKT and The Renal Association, and collaborative work with pharmaceutical companies including joint research grants."

John holds many professional committee appointments, among them Chairman of the Kidney and Pancreas Advisory Group, UK Transplant and Chairman of the Scottish Transplant Group. He is also a Specialist Advisor to the Chief Medical Officer in Scotland.

NCP car parks

NCP car parks have generously agreed to place nearly 200 NHS Organ Donor Register advertisements on hoardings across the country. The adverts will be placed to coincide with key events to increase awareness – during Transplant Week in July and at the end of the 10th anniversary year in September.

Archie Hunter, Media Sales and Added Value Services Manager for NCP, added: "I believe that this is a very worthwhile cause and NCP will be delighted if more members of the public gain awareness of organ donation by the use of the company's advertising resources".

Gateshead people are angels of the north – plus south, east and west

Gateshead has been named the kindest place in the UK, with the highest proportion of people willing to give the gift of life by becoming organ donors after their death.

To date, 36% of the town's population have signed up to the NHS Organ Donor Register (ODR) – more than anywhere else in the country. The Tyneside town is just ahead of Basingstoke in Hampshire, where 35.7% of residents have joined the ODR.

Transplant recipients Scott Thirtle and Elizabeth Norman, who both live in Gateshead, teamed up with the town's famous Angel of the North landmark to encourage more people to follow the town's example and sign up to the ODR.

In Scotland, the "kindest place" accolade was taken by Dunfermline (31.6%), while Cardiff (31.2%) and Antrim (19.7%) were the kindest places in Wales and Northern Ireland respectively.

Mayor of Gateshead, Councillor Patricia Ronan, said: "Gateshead is



Transplant recipients Scott Thirtle and Elizabeth Norman want more people to be angels of the north.

synonymous with the Angel of the North – now the people of Gateshead have shown they are angels of the whole country by offering to become organ donors after their death.

"I hope other towns and cities will be encouraged to follow Gateshead's lead and sign up to the Organ Donor

Register. Each person has the potential to change someone's life."

Sue Sutherland, Chief Executive of UKT, says: "If the rest of the country were to follow Gateshead's example, the register would stand at over 21 million, which could allow many more people to benefit from a life-saving transplant."

Credit: Neil Wasp, 1 to 1 Photography

Jonah Lomu marks return to rugby with appeal to sign up to ODR

Rugby Union superstar Jonah Lomu used his return to the sport to back UK Transplant's 10th anniversary campaign. The New Zealand winger was in the UK to play in former England captain, Martin Johnson's testimonial match.

The 4 June game at Twickenham was Jonah's first since benefiting from a kidney transplant last year.

"I was very lucky to have a close friend who was a suitable match willing to donate one of his kidneys," said Jonah.

"Many people, however, have to wait for an organ to be donated after someone has died. That is why it is so important for more people to sign up to the register – and tell their families they want to help someone live after their death."

Call for action from MPs

Rosie Winterton, Minister of State, has written to all MPs to ask them to publicise the NHS Organ Donor Register in this 10th anniversary year. She says: "If you have not signed up to the donor register yourself and wish to, then do so publicly, urging your constituents to do the same."

Rosie sets out several ideas for MPs to take up locally including photocalls, seeking the support of local companies and councils by taking up UK Transplant's email campaign and including the opportunity to register through local council smartcard schemes which access local council services.

She adds: "You could do a general appeal via your local media urging people to sign the register. You might be able to help constituents understand the issues better by visiting a local dialysis or transplant centre."



Rosie Winterton wants MPs to do more.

Massive scheme to target holidaymakers through new European health card

Eight million organ donor registration forms are being sent to UK holidaymakers in July and August.

The massive mail-out is a joint initiative by the Department of Health and UK Transplant. The ODR forms are being posted with the new European Health Insurance Card (EHIC).

Once the EHIC scheme goes live in September 2005, ODR registration forms will be sent out to everyone who applies for a card. It is anticipated

that this mailing will reach 250,000 homes each month from September. The card enables travellers to get free or reduced-cost medical treatment if they fall ill or have an accident in any of the countries covered by the scheme.

Penny Hallett, Director of Communications, said: "This is an excellent opportunity to reach millions of households and we're delighted to be joining the Department of Health in this partnership.

We hope our leaflets will encourage families to talk about organ donation and prompt people travelling abroad to add joining the register to their "to do" list before they go. We know from a recent opinion poll that many people expect to be presented with an invitation or opportunity to join the register – so that's exactly what we're doing."

UK Transplant will be evaluating the success of the scheme.



Highlights on the high streets

Thanks to the generosity of space sellers, StreetBroadcast, UK Transplant is raising awareness in shopping areas in Coventry, Liverpool, Sunderland, Middlesbrough and North Lanarkshire. The distinctive branding and eye catching message are designed to encourage even more people to sign up to the NHS Organ Donor Register. StreetBroadcast are providing advertising space free of charge in support of organ donation.

Karl Adams, StreetBroadcast Poster Manager said: "We at StreetBroadcast are delighted to support UK Transplant and help with the important work they do in raising awareness of the importance of the donor register. We now have over 200 posters distributed throughout the UK to assist with this goal".

New rose dedicated to the gift of life

A Gift of Life Rose has been specially grown to honour organ donors and their families as part of the 10th anniversary year of the NHS Organ Donor Register. Demand for the rose has been so great that orders are already being taken for 2006!

The salmon/orange climber, commissioned by UK Transplant to symbolise new life, is being launched at the Hampton Court Flower Show in July by Olympic champion and TV star Sally Gunnell.

"Organ transplants are a medical miracle but they would not be possible without the generosity of donors and their families," says Sally. "The Gift of Life Rose is a beautiful tribute to this kindness but also reminds us of the importance of discussing our wishes regarding organ donation with our loved ones.

"I have signed up to the ODR and told my family that I want to help someone after my death."

The Gift of Life Rose is available from Bill LeGrice Roses 01603 784 466 or info@rosebuddies.com. Stocks of this climbing rose are strictly limited for November 05 supply.



Sally Gunnell will be launching the Gift of Life Rose at the Hampton Court Flower Show on 4 July.



Louise Love, donor liaison sister, promoted Transplant Week in Canterbury last year with a balloon release.

Transplant Week 3-10 July 2005

Now in its 15th year, National Transplant Week looks to be bigger and better than ever. Across the country charities, transplant staff, recipients, patients and donor families are planning activities for the week, organised by charity Transplants in Mind (TIME).

Events planned include an "It's a knockout" competition on 3 July in Newcastle, involving transplant patients, medical staff and donor families. Newcastle also hosts a release of 3,000 balloons the following Saturday.

In Wythenshaw, Greater Manchester, an ambitious skydive will be attempted by recipients and hospital staff, and in the Devon village of Spreyton TIME volunteers are organising a 22-mile cycle ride for patients. On 3 July the Donor Family Network are holding a Thanksgiving Service in Great Barr, Birmingham. From Wigan to Woking, TIME volunteers are organising displays in public places including hospitals, libraries, and leisure centres.

UKT is sending out 'street teams' to up to twelve UK locations during the week, with representatives discussing organ donation with passers-by.

TIME's Sue Johnstone says: "There are some really exciting events planned, and so far it looks like it's going to be busier than ever. I'm hoping that the week will give a great boost to the 10th anniversary campaign to get a million new people on the Organ Donor Register."

The Trustees of Transplants in Mind have devised posters to help publicise the week. There is also a range of new promotional items available for purchase from TIME, including a teddy bear, wristband and ruler.

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

Award winning web campaign for UKT

UK Transplant's recent online advertising campaign to promote organ donation has been awarded the winning title at this month's Internet Advertising Bureau Creative Showcase, thanks to an engaging, interactive banner.

The industry-run event is designed to show off some of the best work currently around and UKT's advertisements were produced by Agency.Com who used the line "You can help give someone a second chance at life". The ads demonstrate the benefit of signing up to become a donor.

Creative trio Steven Whiteley, Oly Robinson and Paul Banham from Agency.Com worked together to develop a series of online ads including interactive banners and overlays. As a result of the UKT success, the Agency has been asked to present a case study at a forthcoming seminar on "Outstanding Creative".

Chris O'Shea, founder member of the competition was on the judging panel comprising the elite from the UK's top online advertising agencies. He said, "The transplant donor campaign really hooked me – particularly the flatliner banner. It was so simple, brilliantly demonstrating the notion that death can result in a new life for someone."

Ben Clapp, Creative Director at Tribal DDB was also one of the judges. He said, "The UK Transplant campaign has some beautifully executed work and shows a range of approaches. The campaign presents the viewer with the choices they make in an understated, engaging way."

The campaign can be viewed at http://awards.london.agency.com/coi/uk_transplant/index.html



Poll shows clear gap between support and action

Nine out of ten people agree that it is important to discuss organ donation with those closest to them – but only five out of ten people have actually done so.

The clear gap between support and action is revealed in a survey by National Opinion Polls (NOP) which interviewed 900 people both before and after UK Transplant's radio and online advertising campaign earlier this year.

Those least likely to have raised the issue with family and friends were 16-24 year olds and people over 65. Men were also less likely than women to have discussed organ donation.

Among those who had claimed to have joined the NHS Organ Donor Register (ODR), nine out of ten said they had discussed the subject with someone close to them – suggesting that registration itself acts as a prompt to discussion.

The radio ads featuring five transplant recipients were aired across 66 commercial radio stations and a further 45 voluntary/community radio stations in England, Wales and Northern Ireland during a three week period from 28 February. The advertising campaign, the largest ever undertaken by UK Transplant, was designed to raise awareness of the benefits of organ donation, make people feel positive about donation and encourage more people to add their names to the register.

The advertisements were also used by a further 45 voluntary/community radio stations. On-line advertising was booked on 14 websites, including Wanadoo, Friends Reunited, Red Hot Curry and AOL UK. The NOP survey saw support for organ donation increase with the number of people strongly in favour of organ donation increasing by 5% to 68% following the campaign with those slightly in favour rising by 1% to 20%*.

Despite this support for organ donation, less than a third (29%) of those who said they were aware of the register (equivalent to 90% of the total public) had actually joined the ODR. The vast majority of people interviewed during the research accepted the "moral case" for joining the ODR with 83% agreeing during the post advertising research that if you are willing to receive a donated organ you should be willing to donate your organs.

Awareness of the ODR also rose slightly during the campaign – from 61% to 63% – but a third said they had never heard of the register. Around a third of participants claimed they were likely to join within the next six months.

Reasons given by those questioned for not adding their names to the ODR included – never been asked to join (30%); don't know how to join (22%) and already have a donor card (11%), suggesting a lack of knowledge about how to join and a strong pointer that people expect to be presented with an invitation or opportunity to join.

The high level of claimed awareness of the register combined with positive attitudes towards organ donation, suggests there are few barriers to joining but the immediate need to do so is not recognised.

Ninety-one per cent of people interviewed after the campaign said the ads showed how organ donation can save someone's life.

A third of people interviewed said they had heard at least one of the ads increasing to nearly half (48%) of those who frequently listened to commercial radio.

** A survey carried out for UK Transplant in 2003 showed a similarly high level of support (around 90%) for organ donation in principle.*

Approaching families: the success of pilot workshops for consultants

In the Spring 2005 edition of Bulletin, we reported on training organised by UK Transplant for all donor transplant co-ordinators on approaching families for organ donation. The next phase of this training, using the same American collaborative model, was to set up the first ever workshops in the UK for clinicians.

These were held in April for senior ITU clinicians from West Yorkshire and London, and produced stimulating results for the participants, as well as the American training team. "This project in the UK is, to our knowledge, the largest effort anywhere to make this change in practice. That's one reason we find it so exciting," says trainer Margaret Verble.

The "Delivering bad news and approaching relatives for donation" pilot workshops built on the donor transplant co-ordinators' training and involved co-ordinators acting as

themselves in role-plays. The workshops also covered communication, the timing of talking to families, US research and practice, and a review of the UK National Potential Donor Audit 2003-04.

The significant number of families refusing permission for donation was shown by the Potential Donor Audit as the primary cause of the shortfall between potential and actual donors. The audit also showed that the most important factor in gaining consent was the presence of a transplant co-ordinator, along with a consultant at the interview.

Participants were able to test out their expectations in the role-plays. Dr Tony Shambrook, Clinical Director of Surgery at the North West Wales NHS Trust, attended the West Yorkshire workshop: "In the role-plays we were shown how to introduce the Transplant Co-ordinators as members of the team who have expert skills in such

situations. I found this approach useful, valid and it worked very well in practice."

This part of the workshop also provoked keen interest at the London workshop – participant Dr Sally Wilson, Consultant in Neuroanaesthesia and Neuro-intensive Care at the National Hospital for Neurology and Neurosurgery in London. She said it was very effective to have clinicians taking on the part of relatives: "It gave us a chance to experience how little information is received by people at such a stressful time in their life. I found this a powerful teaching tool and probably the most useful part of the day. The National Hospital will be using elements from the programme in courses on breaking bad news."

Tony observed the effect of consultants and co-ordinators working collaboratively in their discussions with relatives and was able to put it into practice the weekend after the workshop: "The workshop was excellent. It was informative, enjoyable and extremely well organised. I was able to convert the role play into real life - the result was successful, both in terms of care for the relatives and donation."

Workshop facilitators Judy Worth and Margaret Verble not only bring considerable practical and academic experience to these events, including 25 years of research, they also come from donor families.

"The workshop was excellent. It was informative, enjoyable and extremely well organised. I was able to convert the role play into real life."

While they were struck by how British clinicians are "more people-oriented" than their US counterparts ("our doctors relate better to medical technology than to people by the time they get into actual practice"), they noted that several participants appreciated the support the training gave them in handling conversations which can be hard for everyone involved. Judy cited this example: "Several physicians became aware of the kind of confusion families feel over the subject of brain stem death being

death. It's very hard to get that across, and the language traps are considerable."

Comparing the co-ordinators' courses and the intensivists' pilots, Margaret and Judy said they were surprised at first to find very few differences on the courses between physicians' and co-ordinators' reactions to approaching families for organ donation, and concluded that it is because "your co-ordinators are, for the main part, highly skilled professionals".

MORE COURSES

UK Transplant's Director of Donor Care & Co-ordination, Sue Falvey, has announced that more intensivists will have the opportunity to take part in this special programme: "We are delighted with the success of the pilots and workshops will be rolled out across the UK over the next 12-18 months."

Tony Shambrook's advice to potential participants is clear: "If you get the chance to go on it, snap it up."

Using a clinical simulator

A very unusual patient in the Montagu Hospital in South Yorkshire is helping critical care staff in the North Trent region experience the complex demands of organ donation in intensive care. The patient is a manikin programmed to simulate brain stem death, become clinically unstable and require intervention to prevent cardiac standstill. The mock patient is at the centre of an interactive study day programme, which has been funded by a legacy for the hospital, to involve ICU staff in key aspects of organ donation.

"The aim is to improve confidence and competence in clinical staff," explains regional transplant co-ordinator Michael Hope. "Organ donation in intensive care may not be experienced by many members of staff, or only a few times in a year. In the past we've told ICU staff about what we do, but now, with this training, we aim to explain to staff, all of them involved in caring for patients, the role they can play in organ donation. We want to ensure they have the skills and confidence to provide quality care for potential donors and their families."

Regional transplant co-ordinator, Sue Cooke, says recreating the environment of treating a patient in an intensive care unit is very effective: "The simulator responds in real time to treatment changes and may require altered

ventilatory support, fluid resuscitation and pressor support or hormone replacement therapy. Staff have to recognise physiological triggers, such as changes in blood pressure."

The study day includes a brain stem death workshop run by a consultant neuro-intensivist, and communication skills, with training based on the work of Margaret Verble and Judy Worth.

"We have trained 42 nurses and the response has been absolutely brilliant," says Michael. "All local critical care students will now attend the simulator course as an intrinsic part of their training from Sheffield University."

The Montagu Hospital simulator will be presented at a national health care conference in October.



Simulating brain stem death is at the centre of the interactive study day.

Credit: Michael Hope

Boost to black campaign

A campaign to raise awareness of organ donation amongst black and minority ethnic groups is well underway, with support growing throughout major cities in England.

Over 300,000 leaflets and over 1,000 posters have already been distributed by specialist agency partner, MediaReach, who are encouraging local businesses and community groups to show their support and display information about organ donation in London, Birmingham, Bristol, Manchester, Leeds and Nottingham.

High street retail chain Boots has also partnered this promotion and has distributed 44,000 leaflets to shops in key areas.

Stand-up comedian Curtis Walker is again backing UK Transplant's effort. He said: "This is a real issue facing us as black people – but one we can do something about. There are currently almost 400 black patients waiting for a transplant, some of them small children, but as an ethnic group we are seriously under-represented on the NHS Organ Donor Register," said Curtis.



Organ donation provides a focus for discussion amongst members of the black community at the Yes cyber cafe and information centre in Leeds.

In a recent visit to Hype hair salon in London's Balham High Road, Curtis posed alongside salon manager Chester Julien to promote the campaign.

Calvin Rattray, the owner of Hype, said: "Organ donation wasn't something I had really thought about until I was asked if I would display the leaflets.

My customers are now starting to pick them up and talk about them, which can only help the wider black community."

The leaflet distribution has been supported with a wider PR initiative aimed at the black and minority ethnic media, resulting in regional and national press and radio coverage.

Awareness raising at Asian health fair

In March, Luton Teaching PCT used its Diabetes Health Fair to highlight the issue of organ donation among South Asian communities. The event was organised in partnership with local faith communities and well attended by local people.

At the event, Gurch Randhawa, Principal Research Fellow, talked about the potential complications of diabetes which sometimes result in renal failure and the need for dialysis and transplantation. He emphasised the urgent need for more organ donors from the South Asian community.

Religious issues relating to organ donation were discussed by the Chair of Luton's Council of Faiths, Zafar Khan,

and transplant co-ordinators from Addenbrookes' transplant centre were on-hand all day to answer questions about organ donation.

Gurch said: "The PCT wants to encourage debate in open public forums such as this and it was the ideal event to highlight the risk of kidney failure and the pressing need for more Asian organ donors."

In another awareness-raising effort, UK Transplant distributed leaflets at the "Tongues on Fire" three-week Asian Film Festival held in March. The festival took place at various locations in London and was sponsored by the Department of Health.

Organ donation, faith and culture conference

The challenges of tackling the increasing shortage of organ donors, especially from minority ethnic communities, will be discussed at a conference funded by UK Transplant, at the University of Central Lancashire.

The "Organ donation, faith and culture conference", on 22 June, is part of UK Transplant's programme of events to mark the 10th anniversary of the Organ Donor Register. It also develops UK Transplant's commitment to informing more people from minority ethnic communities about organ donation and transplantation issues, and encouraging more to talk about these issues and join the register.

The conference will bring together key community and religious leaders from the North West of England to discuss the issues and devise a 12 month action plan to raise awareness in Lancashire's multicultural community.

The number of people in the UK needing transplants is expected to rise steeply over the next decade. Currently, more than 7,000 patients need a transplant, but in 2004-05, fewer than 3,000 transplant operations were performed, and out of the 750 people who donated organs after their deaths, only 28 (3.7%) were non-white. In the same year, 460 people died while waiting for a transplant – one in seven (17%) from a minority ethnic group.

Kamlesh Patel, Director for the Centre of Ethnicity and Health, University of Central Lancashire, is one of the conference speakers: "This is a crucial issue and one that cannot be tackled by the health services alone; we need to engage with communities and develop a strong partnership through which a real and sustainable change can be achieved."

UK Transplant Regional Manager Steve Bell, who is chairing a session at the conference, adds: "None of the major faiths within the UK have any objection to organ donation or transplantation, in fact many feel that organ donation is a very altruistic and virtuous act. However, there are still cultural objections and in some communities there is lack of understanding."

UKT at summer melas



UK Transplant will be attending four melas this summer to take the organ donation message into local Asian communities. Asian staff will be specially recruited to answer questions about donation and to make people aware of the NHS Organ Donor Register. UKT will be taking a stand to melas in Bradford, Birmingham, Leicester and London.

Crystal Ball

As part of the 15th anniversary celebrations, TIME is organising a "Crystal Dinner and Dance" at The Dorchester in London on 9 July.

150 medical staff, charity representatives and other generous partners will be treated to a glitzy evening of fine food and wine, kicked off by a glamorous champagne reception. There will be an auction of donated gifts, including a Rambo poster signed by Sylvester Stallone, and signed discs from Kylie Minogue, Freddie Mercury and others.

"The event is already nearly a sell-out, and we're delighted with the support we have received from family and friends. We're particularly grateful to Novartis who are helping fund the event," said Sue Johnstone, the event organiser.

BTS conference highlights trends in transplantation

At the British Transplantation Society annual conference, held on 6-8 April in Belfast, 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. Two of the presentations are summarised here.

Life expectancy of liver transplant recipients in the UK

The aim of this study was to compare the life expectancy of liver transplant recipients to that of the UK population.

Data on 3,600 adult recipients who were still alive six months after their first elective deceased heartbeating liver only transplant in the UK (1985-2003) were analysed, and the median life expectancy for different combinations of patient age, sex and year of transplant, estimated.

The life expectancy for various age, sex and year combinations for the UK population were obtained from The Office for National Statistics¹. Using these data the equivalent UK population life expectancy for all combinations of age, sex and year of transplant in the liver transplant dataset were determined.

Although no account has been taken of improvements in the management of recipients and the changing pattern of liver disease, results suggest that adult liver transplant recipients have an average life expectancy of 21.6 years. The average life expectancy of the equivalent UK adult population is 29.3 years, and so on average 7.7 years of life are lost. Furthermore, female recipients lose fewer life-years than male recipients, and younger recipients lose more life-years than older recipients.

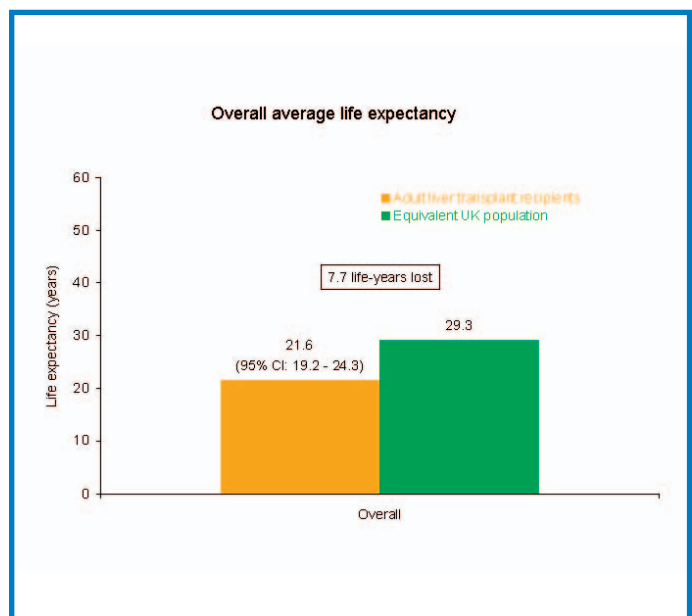
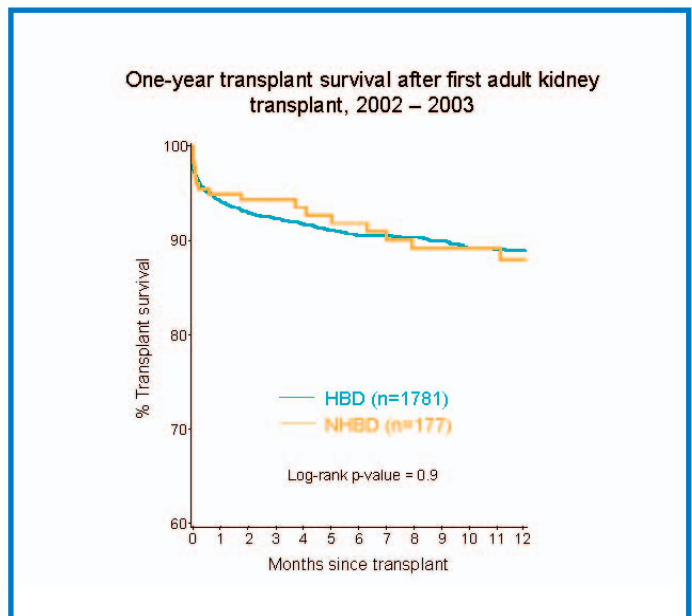
Reference: 'The Office for National Statistics (2004) Table 5.1 Expectation of life at birth & selected age. Population Trends [online], 117 (V2), 62.

Comparison of non-heartbeating and heartbeating donor kidney transplantation in the UK

The number of kidney transplants from non-heartbeating donors has been increasing rapidly in the UK in recent years. This study compared donor and recipient characteristics and one, three and five-year outcome of deceased non-heartbeating donor (NHBD) and heartbeating donor (HBD) kidney transplants.

We analysed 450 NHBD and 9,165 HBD first adult kidney-only transplants performed in the UK between 1995 and 2003. In 1995, 2.5% of all cadaveric donor transplants were NHBD transplants, rising to 9% in 2003. Differences in donor and recipient characteristics can be seen in the table below.

In general, one, three and five-year transplant survival (death with function treated as failure) rates were poorer for NHBD transplants than for HBD transplants in the earlier years studied. More encouragingly, one-year transplant survival was comparable for NHBD transplants (88%, 95% CI 82-94%) and HBD transplants (89%, 95%, confidence interval (CI) 87-91%) in the most recent years analysed (2002-2003). There remained no difference in outcome after adjustment for known risk factors. Finally, in terms of patient survival, no significant differences between the two donor groups were identified.



Training the eye retrieval co-ordinators

In May, UKT hosted two days of training for the recently appointed eye retrieval co-ordinators. The co-ordinators are from the eight special eye retrieval centres, funded by UKT, to increase the number of cornea transplants.

Peter McDonnell, Chairman of OTAG and one of the key advocates for the new scheme told co-ordinators on the course: "Up until now eye retrieval around the country was on an ad hoc local basis. There was no national scheme for tissue and eye retrieval so the service provided was very variable. We are very pleased with the establishment of the eye retrieval centres and things look very encouraging."

Peter emphasised to the participants that an important part of their role is promoting donation and staff education. He said: "The key thing is to ask the relatives. You can't be everywhere to ask every family, so you will have to encourage other staff to approach families to ask about donation. You will need to educate staff on the ground, but also get senior doctors and trust management on board."

"You will need to establish a good working relationship with local tissue and transplant co-ordinators, so that you are all working with the same aim. We need to change the culture, to get everybody thinking about asking relatives about donation."

Karen Draper, Senior Tissue Donor Co-ordinator for the Bristol region, facilitated the training days on behalf of UKT. Its aim was providing a base of knowledge for best practice and enabling the new eye retrieval co-ordinators to get together for support and to discuss working practices with each other.

Karen commented: "We've had good feedback from the participants. The training days have generated a lot of discussion and people have been able to air anxieties and raise issues that they have around their role."

"The new co-ordinators come from a wide variety of backgrounds – some who have been doing the job already and others with all kinds of nursing backgrounds."

The retrieval team in Bolton NHS Trust is made up of four staff who are seconded for one day a week to the role, plus two full time staff. The team has only officially been in place since



The bereavement and donor support team in Bolton. L to R Liz Kiely, Julie Bramwell, Lynette Halliwell, Elsie Fish, Eddie Davies.

1 April 2005 and, in the first 6 weeks of the scheme, has already retrieved 22 corneas from 11 donors, exceeding initial expectations.

Each member of the team works with nursing staff on different wards, giving them training to help them identify which patients could donate. So far, the team members have found their colleagues very positive and supportive of their new roles, but they recognise that raising awareness is the key.

Liz Kiely, the team leader, explained: "Our training makes people think about patients that they have cared for on the ward, people who could have been donors, but whose families were never asked."

Elsie Fish, an ophthalmic theatre nurse, said: "Some believe that it will make it harder for the family if you ask them. But it's actually a very positive thing. They have a fear of approaching the family. Our role is to give them that confidence."

The co-ordinators have had to learn a whole range of new skills, including enucleations (eye retrieval) and bereavement counselling.

Julie Bramwell, a member of the team who works on a surgical ward, said: "I had a huge phobia about eyes before I took on this role. I knew I would have to do retrievals and I was really nervous. I also felt under a lot of pressure to get it right, as I knew that donated corneas are really precious. But, I also knew that if we weren't here the retrieval wouldn't go ahead."

Liz concluded: "Every member of the team is well motivated with a real determination to help people and make a difference. We understand that the shortage of corneas is a problem that can be overcome and that our role is integral to achieving this."

- **3,735 corneas were retrieved in the UK in 2003-04**
- **Not all donated corneas can be used for surgery and, of these, 2,365 grafts were carried out**
- **This compares to 47,000 grafts carried out in the USA in the year 2000**
- **This equates to:**
40 grafts per million population in UK
170 grafts per million population in USA

...Neville Jamieson

Transplant and Hepatobiliary surgeon Neville Jamieson studied Natural Sciences in Cambridge before moving to University College Hospital in London to complete his clinical training.

Less than two years later he made a life-changing move to Addenbrooke's transplantation unit led by Professor Roy Calne.

His interest in transplantation rapidly developed and after working in Cambridge as a registrar and senior registrar in General Surgery and Transplantation moved on in 1986 to a year as Research Associate and Instructor at the University of Wisconsin. There he carried out groundbreaking experimental liver transplant work in the use of UW solution, a synthetic solution designed to increase the longevity of organ storage, and was awarded a Hunterian Professorship in 1988.

Neville has been a member of UKT's Liver Advisory Group since 1987. He writes and lectures on transplant issues.



Q What prompted you to specialise in liver transplantation?

A I was first a Senior House Officer in the transplant unit at Addenbrookes in 1979 with Sir Roy Calne when liver transplantation was still in its relatively early days and was working in Cambridge when the 100th liver transplant was performed. Being part of liver transplantation when it was still far from being accepted was both exciting and stimulating and led to an enthusiasm for liver transplantation which has continued (alongside my other transplant interests) to this day.

Q What else might you have done?

A Vascular surgery or perhaps given slightly different circumstances nephrology!

Q What aspect of your current role gives you most satisfaction?

A Seeing sick patients transformed by a successful transplant going back to enjoying a full normal life.

Q What aspect do you least enjoy?

A Not being able to treat all the patients who could benefit because of the shortage of donor organs.

Q What has been the greatest success so far in your career?

A The demonstration of the effectiveness of UW solution for liver preservation during my time in Fred Belzer's department in Wisconsin in the mid 1980s and seeing its subsequent introduction into clinical practice worldwide. This work formed the basis of a Cambridge MD thesis and led to the award of a Hunterian professorship by the Royal College of Surgeons of England.

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

A Be careful, be patient and always pay attention to detail. Always be ready to learn new lessons and always strive to do better.

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

A Improved results. From being a radical high risk procedure with often poor survival figures transplantation has come to be recognised as a standard treatment with excellent outcomes. We are now looking at long term issues such as quality of life and avoidance of immunosuppression related morbidity instead of the earlier need to concentrate our efforts on improving short term survival.

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

A Attempt to drive a change in attitude in the non transplant medical community and society at large where the possibility of organ donation after death is accepted as a priority and ensure that no organ which could be used for transplantation is wasted.

Q What is your most memorable moment?

A The excitement generated after I presented successful 24 hour liver preservation with UW solution in Pittsburgh in 1987. Or perhaps that should read the birth of my three children!

Q How do you relax?

A Music, hill walking in the Lake District, fishing, motorcycling and spending time with my wife and children.

Q What would you choose for your epitaph?

A I was tempted to steal Spike Milligan's "I told you I wasn't well" but probably something like – "He tried hard and made a difference".

Ocular Tissue Advisory Group

OTAG met on 26 January 2005

- Work is ongoing to develop a process of collating information from independent units in lieu of a national registration system.
- The new EU directive (2005/23/EC) requires units storing whole fresh eyes to either set up a tissue establishment to cover these activities and apply to MHRA (Medicines Healthcare Regulation Agency) for accreditation or to set up a third party agreement with an accredited tissue establishment.
- Work is progressing on the addition of further codes to the UKT database to accommodate future changes such as the recording of further splits of corneas and limbal cells. Minor modifications are being made to the list of contra-indications to corneal transplantation. These will be added to the UKT website.
- Clarification is being sought from the Department of Health on the existing regulations relating to Group 2 patients. Any person from an EU country with an E112 form is entitled to Group 1 status in the UK.
- Tissue donation is an area where the National Blood Authority and UK Transplant overlap and it is not known how this will affect the work of the eye banks and ocular tissue transplant units. NHS Blood & Transplant will review the future employment of co-ordinators to address differences in the methods of employment.
- The eye retrieval centres are making good progress in appointing new staff.
- A proposal has been approved for the completion of Ocular Tissue Donor Information Forms by the transplant/tissue co-ordinator rather than the eye retriever. However, further work on standardising practice within trusts is required.
- A protocol on dealing with adverse incidents following ocular tissue procurement by ophthalmic staff will be circulated to all regional representatives on OTAG. As of April 2005, to aid the management of stock, a proposal was approved to limit centres to a two-month window when ordering ocular tissue for a proposed graft date.
- Regional representatives were asked to remind centres of the mandatory requirement of the Royal College of Ophthalmologists to complete transplant record and follow-up forms.
- An amendment to the Tissue Donor Information Form is to be agreed to reassure donor families that ocular tissue issued and not used is appropriately disposed of.

Cardiothoracic Advisory Group

CTAG met on 2 March 2005

- Under the Freedom of Information Act a request was received on cardiothoracic outcome data. Following consultation with NSCAG (National Specialist

Commissioning Advisory Group) it was agreed that this would be supplied in the form of the "End of year report from the Audit Steering Group to NSCAG" dated September 2004. Consideration is being given to the release of this data on an appropriate website.

- Members discussed the risk versus benefit to the transplant recipient of the need to test tissue donors for variant CJD. Approximately 50% of solid organ donors also donate tissue and are therefore likely to be tested. As part of the normal consent process and using data currently available, patients should be advised of the small risk of transmitting **an infection** such as vCJD or HIV from the donor organ. There was concern on how patients might perceive this information and the impact on donation. If a positive result were confirmed following transplantation then the recipient would need to be advised on the grounds of public health.
- Transplantation of legally incompetent adults is not general practice, particularly as all patients need a degree of post-operative aftercare. However, each case should be decided on its own merits and the appointment of authorised medical proxies, as proposed in the Mental Health Bill currently going through Parliament, should assist decision-making.
- As at February 2005 centres had already used this year's allocation of urgent heart registrations and members agreed that an audit be carried out to assess the appropriateness of patients being listed on the super-urgent scheme prior to any changes being made, and to consider an additional proposal that the payback be given to the local offering centre rather than the pool. In the meantime, centres will continue to register patients through the urgent heart scheme for the remainder of the financial year, putting aside the previously agreed limits. Members of the cardiothoracic audit steering group will define the urgent heart scheme clinical criteria and advise UKT on how to audit best practice.
- Due to a dramatic fall in the number of donors, the transplant targets for lungs under the Republic of Ireland contract were not met. It is anticipated that the contract will continue for a further year.
- A position statement from UKT on living donor lung transplantation is being considered by NSCAG (National Specialist Commissioning Advisory Group). Further work will need to be carried out on producing associated standards and including this within the current audit process.
- At a meeting in January of the National Heart and Lung Transplant Standards Development Group, it was agreed to revise the national standards before June 2005 and that there should be one document containing sections for heart and lung transplantation and ventricular assist devices. Arising from a recent incident of withdrawal of consent by donor relatives and the potential impact this could have on patients already committed to transplant surgery, UKT agreed to clarify the legal position with centres and advise them on best practice in this type of situation.

Transplant Co-ordinators Advisory Group

TCAG met on 16 March 2005

- The donor record forms used by cardiac centres will be standardised in an effort to improve reported delays in responding to offers or accepting/declining hearts and lungs.
- A joint working party has been established to look at the requirements of the new organ box contract in light of the merger of NBA and UKT. As an interim measure it was recommended that the documentation to accompany the organ be placed in an envelope, the back of which is then signed and sealed by the co-ordinator.
- Correspondence was received from an ambulance service in Wales advising that they are normally notified of potential recipients in their area who may need to be brought to hospital for transplantation at short notice. However, following this initial contact no further information is received and the ambulance service is unaware of any developments regarding the patient's situation. A review of the current practices within cardiac and liver units was agreed in order to measure the need and feasibility of providing information to the ambulance service on a regular basis.
- A report was received on a review of the Donor Liaison Scheme and its impact on organ donation. The scheme was found to have increased the number of tissue donors and appears to have had an impact on public and NHS awareness of organ donation locally. At the expiry of the service level agreement for the current, active donor liaison programmes the successful elements of the scheme will be incorporated in alternative new initiatives. Clarification of the policy for disposal of corneas issued but not transplanted was requested. It was confirmed that in each case the advice of the relevant trust should be sought regarding its policy on the disposal of tissue. Each trust is responsible for ensuring that all staff are aware of the policy.
- No major problems have been experienced in implementing the patient consent pilot scheme within cardiothoracic and liver units. There is concern within renal units, however, as a considerable number of dialysis units register patients themselves with the patient only attending the transplant unit for the operation. In light of this it is proposed that a further pilot, involving random dialysis units, will be undertaken. It was noted that in 74% of cases the interview for consent is carried out by transplant co-ordinators, indicating there may be implications for transplant co-ordinators when the scheme rolls out. The numbers of people accessing the ODR were reported as disappointing for the third quarter of 2004 and representatives were asked to encourage all health care professionals to request access.
- Regional Managers are to reiterate to units the importance of working in accordance with the Donor Family Care Policy in terms of forwarding letters between donor families and recipients.

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

PTF met on 15 April 2005

- Initial arrangements have been set up in principle for UKT to advise Diabetes UK of any pancreata not being used for transplantation, although work is still ongoing to improve the robustness of the process. The standard operating principles are currently being compiled between UKT and the Diabetes UK islet consortium and these will be circulated. The Department of Health will be approached to provide clarification on whether islet transplantation is classed as clinical practice or research as this affects the consent required to use the organs.
- The issue of patients who are registered for a kidney/pancreas transplant also being eligible to receive a kidney-only transplant was considered. It was agreed that at this stage it would be inappropriate to abolish dual registration but that centres should encourage non-sensitised patients to single register where possible. It seems inevitable that a small number of patients will always require the option of double registration.
- There was concern over the effect that the possible testing for variant CJD of solid organ donors who also donate tissue could have on the potential donor population. The following recommendations were made: solid organ donors who are not tissue donors should not be tested at present where testing takes place on tissue donors who are also solid organ donors then the spleen should be used for testing, as opposed to the tonsil. This should also apply during the pilot scheme the implications of the tests should be discussed with the recipient during the consent process recipients should also be advised if they receive an organ from a donor who has subsequently been found to have a positive test result and guidelines need to be produced on how to deal with this type of situation.
- A total of 79 pancreas transplants were performed in 2004, compared with 54 in 2003. The increased activity in pancreas transplantation reflects both the new sharing scheme and NSCAG funding. There were concerns surrounding the fact that diabetic patients registered for kidney-only transplants are waiting longer than those awaiting simultaneous pancreas/kidney transplants. Approval to change the upper and lower age limits for pancreas donors to 50 and 8 years respectively will be sought at the next meeting of the Kidney & Pancreas Advisory Group.
- It was agreed that pancreata from blood group O donors may be transplanted in groups O or B but not into A or AB, and that blood group A or B may be transplanted into AB. Concerns were raised around the zonal arrangements for the retrieval of pancreata. The funding from NSCAG should cover the provision of two retrieval surgeons, the perfusion solution and a self-sufficient retrieval team. It was agreed that each pancreas retrieval team is responsible for making their own arrangements to provide a scrub nurse, either by sourcing their own or by setting up formal arrangements with the liver scrub nurse. Additionally it was agreed that

the pancreas team would also usually remove the kidneys, as they would normally be transplanting at least one of the kidneys.

- As part of the NSCAG contract centres are required to retrieve within their zones. Concerns were raised regarding the accuracy of data showing the reasons cited by centres for non-retrieval of pancreata as some of the reasons cited were felt to be incomplete. This data will be monitored on an ongoing basis. A new pro-forma listing classifications under which refusals are recorded is to be compiled for review with the transplant co-ordinators in order to improve the accuracy of reporting.
- Only 33% of simultaneous pancreas/kidney patients were

listed pre-dialysis and only 10% received a pre-emptive transplant. However, during the same period only 22% of kidney-only patients were listed pre-emptively with only 6% receiving a pre-emptive transplant.

- A study into the survival of livers retrieved using alternative perfusion techniques (via the aorta only or via the aorta and portal vein) found no significant difference between the two methods. The number of transplants was small and the data will be revisited in a year's time. Liver units have confirmed they are happy to use only aortic perfusion when the pancreas is being retrieved.
- As at 1 April 2005 the form return rates have significantly improved for all centres.

Accessing the ODR

Thank you to the 12,315,000 people – over 20% of the UK population – who have said they want to help others live after their death by joining the NHS Organ Donor Register.

Between 01 January 2005 and 31

March 2005, 261 requests were made to access the register:

- **27% of all cornea donors and**
- **22% 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.

RESOURCES

Thank you card

UK Transplant has produced a "thank you" card for transplant co-ordinator teams, donor liaison nurses and others to use.



They can be used to thank partner organisations or individuals who have helped out eg in promoting the 10th

anniversary, in helping out with photos, for companies who offer support to you in kind or other health professionals.

To order these cards please contact Nicole Sutherland at UK Transplant on: 0117 975 7490 or Nicole.Sutherland@uktransplant.nhs.uk

Centre-specific information

For the first time, information about all UK kidney transplant centres has been published on the website. These centre-specific reports can now be accessed from the Statistics section of the website.

The reports provide information about kidney donor, transplant list and transplant activity for all centres and is based on data extracted from the National Transplant Database maintained by UK Transplant.

The data covers three years and will be updated once a year. It is anticipated that this information will be used by clinicians, patients and other members of the public.

Users will, for example, be able to find out how soon patients received a transplant after being listed, and the numbers and survival rates of transplants at a specific centre.

Also new to the website in the About Transplants section are some frequently asked questions about kidney transplants. These questions and answers have been put together with the help of UKT's Patients' Forum and include information about people registered for a transplant, factors which affect the success of transplants and the difference between heartbeating and non-heartbeating donation.

Players pass it on

Players from leading rugby and football teams across the North of England are giving a **huge boost to organ donation through a sporting campaign.**

The campaign, with a slogan "Become a life-saver. Pass it on." aims to encourage people to sign onto the register and importantly to pass information on to their family and friends about their wishes.

The idea behind the sporting campaign began in Manchester with the support of transplant patient John Martin. Well placed to make things happen, John is Managing Director of the JJB stadium in Wigan, home to both Wigan Athletic football club and Wigan Warriors rugby league club.

With this impetus the Manchester transplant team put in a successful bid for some 10th anniversary funding from UKT. The transplant team kicked off the campaign at a football game earlier this season.

Sue Frew, transplant co-ordinator at Manchester Royal Infirmary and one of the main driving forces behind the campaign, said: "This was a big success, and the football club agreed to take on more promotion work next season – even better now they are celebrating their promotion to the premiership!"

Then the idea was taken to Leeds. Gary Hetherington, Chief Executive of the Leeds Rhinos and Leeds Tykes rugby league teams, was keen and, with input from the Leeds transplant co-ordinators, took their plans to the Rugby Super League.

As a result, there is now a grand plan to promote organ donation during Transplant Week at six rugby matches.



Wigan Athletic and Wigan Warriors players launch the sporting campaign at the town hall.

"The Super League also celebrate their 10th anniversary this year, and have said that we can repeat our promotion at the grand final in October, which is fantastic! We're also planning to extend the campaign to other sports and hope that Rugby Union will take the idea on board," said Sue.

A groundbreaking multi-professional transplant degree has been developed by NHS Lothian University Hospitals Division in collaboration with Napier University Edinburgh.

This is a new venture aimed at providing continuing professional development opportunities for staff working within the specialities of transplantation and intensive care. The first of its kind, prior to this there was no formal accredited training available in Scotland relating to liver, renal and pancreas transplantation for nurses, and allied professionals.

Yvonne Perry, Transplant Unit Education Co-ordinator at Lothian NHS Board said, "The success of the Transplant Unit in Scotland resulted in the development of this formal accredited professional development course for staff. It is envisaged that the course will enhance the knowledge and skill base of professionals caring for organ donors, recipients or patients on the waiting list".

For further information relating to the programme please contact Yvonne Perry, Transplant Unit Education Co-ordinator 0131 242 1710.

In April **transplant co-ordinators in Belfast arranged a "Gift of Life" study day** for 70 ICU and theatre nurses to promote organ donation.

Heather Savage, transplant co-ordinator at Belfast City Hospital Trust, said: "Everyone enjoyed the day and the evaluations were good. One evaluation stated: 'In all of my 25 years of nursing this is the best and most worthwhile study day I have ever been to'. This is the second year we have organised the day and we are hoping to make it an annual event."

On 11 May **the first Leeds, Liverpool and Manchester paediatric symposium** was organised by donor transplant co-ordinators. The event was attended by more than 100 delegates who evaluated the day as excellent.

Jayne Fisher, transplant co-ordinator at St James' University Hospital, said: "Eminent speakers shared their experiences on a range of topics including difficulties in diagnosing brain stem death in children, donor management and how we give all families of potential paediatric donors the right to choose in end of life decisions."