

bulletin

NHS

UK Transplant

The newsletter for everyone involved in organ transplantation and donation
Issue 57 Winter 2005

In this issue: Chris Rudge is UKT's new Managing Director. New NHS Blood and Transplant board. Celebrating 100 years of cornea transplants. Will hepatitis C overwhelm the liver transplant programme? National tissue banking programme. Living liver transplant programme to start in Scotland. Appointment with Bill Fullagar.



This is the second edition of the UK Transplant *bulletin* since the establishment of NHS Blood and Transplant (NHSBT) on 1 October, and now is a very good time to take stock of the situation.



There was considerable concern and anxiety when the decision was announced – over a year ago – to merge UKT, the NBS and BPL into a new single Authority as part of the overall Arm's Length Bodies Review. However at last it is possible to see more clearly the shape and character of the new organisation, and I have to say that I am extremely encouraged by the way in which things are developing.

The key initial decisions about the organisation that have been made are now being put into effect, and I am firmly of the view that most, if not all, of the worries about the future of UKT can be laid to rest. The Chairman and Chief Executive have, I believe, made it plain that corneal and solid organ transplantation are fundamental to the future success of NHSBT and are very clear that UKT is an equal partner in the new organisation.

I cannot say how privileged I am to have been appointed as Managing Director of UK Transplant, although to succeed Sue Sutherland is somewhat daunting – if only she had been a little less good I may have been in with some sort of a chance!

My optimism about the current arrangements and the future is in no way dimmed by the very obvious challenges facing NHSBT – whilst some changes are inevitable I feel that UK Transplant is very well placed to cope with the demands that will be made of us.

Within the overall umbrella of NHSBT we will, for the foreseeable future, maintain the name and identity of UK Transplant and will continue to have a very clear focus on doing what we have been doing over the past four years or more – working to promote knowledge and approval for donation amongst the general public whilst doing everything possible and practical to increase organ and tissue donation.

Another new organisation that is now essential in our efforts to increase organ and corneal donor and transplant numbers is the Human Tissue Authority (HTA). Established as a regulatory authority following the Human Tissue Act 2004 (that comes into force in April 2006) the HTA is chaired by Baroness Hayman and there will be a full article about it in the next edition of the *bulletin*. However, it is clear at this stage that we must continue to develop our very good working relationship with the HTA.

The practical frameworks for the consent process that will govern all organ and tissue donation from deceased donors are being developed after consultations. UK Transplant and the British Transplantation Society are working to establish appropriate clinical criteria for paired and altruistic stranger donation from living donors. The mechanism for independent oversight of all living donor transplants is also currently being developed by the HTA.

Change can always be unsettling, but it can also offer opportunities. I am passionate about transplantation and passionate about the role that UKT can play alongside the thousands of people working in organ donation and transplantation throughout the NHS. We can and will continue to make a difference.

Chris Rudge
Chief Executive – UK Transplant

bulletin

IS PUBLISHED QUARTERLY ISSN 1472-0507
Copy date for Spring 2006 edition 6 February 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
Produced by Picador Design Consultants

*Front cover picture:
Tracey Foster, photographed by Allan Grainger,
helps celebrate 100 years of cornea transplants
(see story opposite).*

Copyright and Liability

2005 UK Transplant. All rights reserved. No part of this publication may be reproduced or transmitted in any form or by any means, including photocopying and records, without the written permission of the publishers or, where appropriate, the author of the article. Such written permission must also be obtained before any part of this publication is stored in a retrieval system of any nature.

Opinions expressed by a contributor to this *bulletin* are not necessarily those of the editor or of UK Transplant and neither the editor nor UK Transplant accepts any responsibility or liability in respect thereof or any other information contained in this publication.

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

Survey reveals eyesight is our most valuable sense

Celebrating the “gift of sight” was the focus of a special initiative designed to mark the 100th anniversary of the world's first successful cornea transplant on 7 December 2005.

A national survey was commissioned by UK Transplant to help provide additional news angles for supporting publicity surrounding the anniversary. It revealed that 84% of people count their eyesight as their most valuable sense.

The National Opinion Poll survey of 1,000 people also revealed that respondents' “favourite sight” experienced in 2005 was England winning the Ashes (30%), followed by the Live 8 concert (18%) and Ellen MacArthur's record breaking voyage (15%).

When asked what they most value being able to see, 90% of respondents said “a loved one”, followed by 83% who said “seeing new places” and 73% who said “watching the sun rise or set”.

When asked whose eyes they would most like to live through for a day, 21% said Richard Branson and 16% said their partners. And in response to what landmark they would most like to see Niagara Falls came top with 23% of votes.

To add further weight to the publicity, UK Transplant asked 10 famous photographers to capture the favourite sights of people who had either received corneas or were still waiting for a transplant. The photographers included Rankin, who takes



Ikram Haq's life has been transformed thanks to two cornea transplants that have enabled him to see again. His “favourite sight” is kickboxing and has been captured by Rankin, who takes photographs for the Queen.

photographs for the Queen, and celebrity photographer David Loftus.

Eye banks, eye retrieval centres, hospitals and charities throughout the UK have been celebrating the centenary, helping to gain local media coverage and highlight the need for more donors.

To find out more about the survey and to see the top photographers' picture gallery see the website: www.uktransplant.org.uk/cornea



Two cornea transplants have given Tracey Foster a precious gift that she thought she may never see again – the sight of her three young children growing up.

Living donor renal forum

The second meeting of the British Transplantation Society Living Donor Renal Transplantation Forum took place in November 2005.

The forum is co-chaired by Mr Paul Lear, Consultant Surgeon, and Lisa Burnapp, Consultant Nurse and brings together colleagues with a range of professional backgrounds with an interest in living donor renal transplantation. Particular thanks are due to Sue Lawrence, local organiser, Cindy-Lee Bright at the BTS Secretariat and the corporate partners, all of whom supported the meeting.

The meeting explored the initiatives which have been implemented to increase the numbers of pre-emptive kidney transplants for both adult and paediatric patients.

Discussion centred upon modernising the approach to improve the accuracy of the timing of the transplant, tailoring donor and recipient assessment to meet the required timeframe and maximising choice for patients at an early stage.

Developments were reported from the Renal Taskforce (the joint industry, Department of Health and UKT project) including the results of two surveys summarised by Fiona Biggins, Live Donor Co-ordinator at Royal Preston Hospital. These surveys are part of the 18-month pilot of the two living donor co-ordinator posts in Preston and Wolverhampton.

Survey findings

Two research projects on living kidney donation have been carried out in 2005: an online public survey to assess public attitudes, and a survey amongst healthcare professionals to assess their current knowledge and practice.

The public survey took place in May 2005 and was carried out by You Gov with a sample size of 2,114. It was found that the public had a good awareness of living donation with 93%

understanding that you can survive with only one kidney. When asked whether they would consider donation themselves 52% of 18 - 29 year olds said yes, with figures decreasing to 44% for 30 - 50 year olds and 38% for those over 50.

Reasons given for not considering donation included the risk to long-term health, surgical risks, damage to the remaining kidney and, most of all, the possibility of renal failure for the donor.

Respondents identified a need for improving general knowledge of the donor process but were mainly confident that healthcare professionals would deliver a truthful account of what living kidney donation would involve. There were a surprising number of respondents who presumed that they would not be a suitable match. Very few respondents considered religious and cultural reasons as barriers to donation.

When asked whom they would consider donating to, the results were reflective of current practice with close family members being the most likely group followed by friends and extended family members.

The healthcare professional survey took place at the Royal Preston Hospital and New Cross Hospital in Birmingham in August 2005 – as part of the Renal Taskforce pilot.

99 questionnaires were completed, predominantly by dialysis nurses and nephrologists.

64% of respondents said that nephrologists were the first point of contact to introduce information about living donor transplants (LDTx).

Although 92% agreed that discussing pre-emptive living donor transplantation with the potential recipient would be most beneficial, only 50% actually do this.

The most common reasons given for not discussing the option of LDTx were that it was "not my job" and "I'm not informed enough".

Only 36% thought they had adequate knowledge of LDTx, with 96% saying that they would benefit from education about LDTx.

When giving information to patients most respondents said the best methods were through booklets and direct contact with patients and donors. 73% said that better quality information was needed.

These survey results will be used to further inform the Renal Taskforce pilots, with the aim of increasing the number of patients choosing live kidney donations.

Patient information initiative

The Renal Taskforce already has an information initiative underway from which new booklets have been produced. In addition a DVD/video for potential living donors has been produced supported by Guy's & St Thomas' Charity. It is based upon a model from the University of Minnesota, USA, and comprises a series of "talking heads" from members of the healthcare team involved in assessment and surgery.

The generic content is designed to be appropriate to all recipients and donors considering the option of living donation and offers them the equivalent of a multi-professional clinic visit that they can view with their families prior to attending the clinic, so that they arrive better informed and armed with the questions they want to ask.

The DVD is being piloted at Guy's and St Thomas' and in Preston and Wolverhampton to assess the potential for future roll-out. Feedback from patients and healthcare professionals will be an important measure of its success.

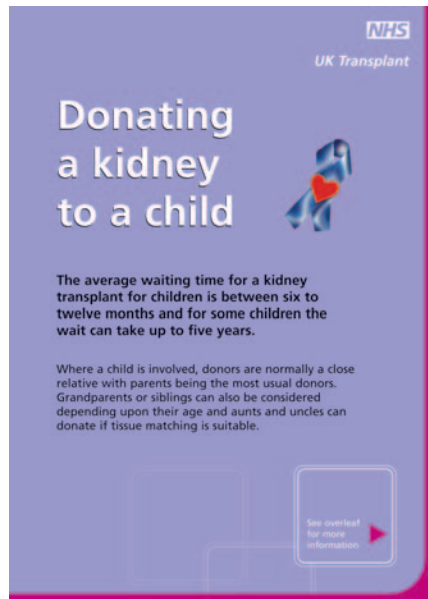
Cont.

New information for parents thinking of donating a kidney to a child

UK Transplant has produced a new insert about donating a kidney to a child. This forms part of the existing leaflet called *Could I be a living kidney donor?* and the two leaflets should always be given out together.

The insert answers questions including "Will I be operated on in the same hospital as my child?" and "Who will care for my child while I am in hospital?"

It is available from the Organ Donor Line as part of the *Could I be a living kidney donor?* leaflet.



Accessing the ODR

Between 1 July and 30 September 2005, 747 requests were made by authorised staff to access the NHS Organ Donor Register:

- 31.9% of all cornea donors and
- 23.7% of solid organ donors

were found to have registered their wishes on the register.

Scots challenged for being 'all talk and no action'

A major direct-response campaign in Scotland has recently been launched to get more people signed up on the NHS Organ Donor Register.

The promotional strategy in Scotland in recent years has been to encourage people to "talk about it". However, with imminent changes in legislation, and given that over 90% of Scots are in favour of organ donation but only 27% are on the register, it was felt that the time was right to launch a major recruitment drive. The Scottish Executive campaign is designed, therefore, to prompt people to act on their intentions.

The subject of organ donation receives a significant amount of media attention in Scotland, and real-life case studies form the backbone of the communications campaign. Unusually, the campaign is PR led. True stories are seeded into the national newspapers, building awareness of the issues and creating a sympathetic audience, while hard-hitting, direct response press adverts are placed to coincide, encouraging

immediate action. This obviously takes close co-ordination, but it also means that the effectiveness of each medium can be closely measured.

The Scottish Executive tested a series of creative ideas with the public and they found that support for the winning idea was virtually unanimous.

Moira Scobbie, Senior Marketing Manager at the Scottish Executive, said: "The public felt it had the right degree of bluntness, and it made them feel guilty for being 'all talk and no action'.

"Not only did the public favour this campaign, but it was widely recognised by UK Transplant, the Scottish Transplant Group, and the Health Department of the Scottish Executive, as being exactly the kind of advertising required to get people signed up.

"It is, undoubtedly, a dramatic departure from the last campaign, but with 63% of Scots still not on the register, the time has come to be bold."



Ulster pharmacies unite to spread the gift of life message

Offering the gift of life in Northern Ireland has become much easier thanks to every pharmacy in the Province now stocking leaflets encouraging people to sign up to the NHS Organ Donor Register (ODR).

All 510 pharmacies – from independently-owned stores to multiple chains – are displaying the leaflets in a joint initiative between the Pharmaceutical Contractors Committee and UK Transplant.

Up to 10,000 copies of UK Transplant's *Signed Up Yet?* leaflets are being distributed around the pharmacies to encourage more people in Northern Ireland to join the 12.8 million people throughout the UK already on the ODR.

Eleanor Donaghy, regional transplant co-ordinator based at Belfast City Hospital, said: "Northern Ireland has historically been under-represented on the register, but we are catching up with the rest of the UK and schemes such as this will help continue that."

Sheelin McKeagney, Committee chairman, said: "Pharmacies are an intrinsic part of the community in every town in Northern Ireland, visited by over 120,000 people every day. They provide an invaluable service with health professionals on hand to offer advice or reassurance immediately on a wide range of medical issues.

"We believe that by placing the leaflets in stores many more people will be encouraged to think about how they can offer the gift of life after their death."

Send a Christmas e-card!

UK Transplant has designed an emailable Christmas card with a click-through link to register on the ODR online. Clare Hanson-Kahn, UKT's Publications Manager said: "This is the first time we've produced an email card which we hope will boost numbers to the register. It's an animated design with music attached and we are hoping that people will want to send it to their family and friends as well as to their professional contacts. We'll be able to monitor how many people who receive the card go on to register on the ODR."

To use the card, simply send an email with the following link which will open in our website:

www.uktransplant.org.uk/christmas



Eleanor Donaghy and Sheelin McKeagney making sure that registration leaflets are prominently displayed.



Milestone pancreas transplant operation

The number of NHS patients benefiting from a life-changing pancreas transplant in a year has hit treble figures for the first time.

The 100th patient to receive a donated pancreas underwent the operation on 7 November at Addenbrooke's Hospital, Cambridge – the hospital where the surgery was pioneered in 1979. The landmark operation was on a 43-year-old man suffering from chronic Type 1 diabetes.

Health Minister Rosie Winterton announced in November 2003 that the number of pancreas transplant operations carried out by the NHS were to be trebled from 54 performed that year to 150 per year by 2009.

UK Transplant's Managing Director Chris Rudge said: "This is fantastic news for pancreatic transplantation in the UK and shows that we are well on track to achieve the government's goal."

Making a drama out of the organ donation crisis

Actor Chris Lillicrap has made a drama out of organ donation – in a bid to “give life”.

Chris, who delivers TV and radio techniques training for UK Transplant, has written extensively for TV and the stage.

His production *Give Life*, which is sponsored by the Astellas Transplant Foundation and supported by UKT is aimed at educating young people on the issues surrounding organ donation and transplantation, creating awareness and encouraging discussion.

In a tight three-week schedule during September Chris and his cast from the Proper Pantomime Company toured 29 schools in Berkshire, the east midlands, Hampshire, Oldham and Manchester. The project was considered so successful that the Foundation has agreed to fund a further tour of 60 schools in February and March 2006.

Give Life is targeted at year six pupils (aged 10 and 11), and treats the youngsters as a studio audience participating in a live TV show. Pupils are asked questions about organ donation and transplantation and given the opportunity to “ask a friend” or seek the opinion of the “studio audience”.

During the hour-long presentation the youngsters were given the chance to discuss and voice their opinions about organ donation.

Chris said: “The response from schools was fantastic. The demand was such that we could have easily doubled the number of visits.

“On the first day the headmaster at one of the schools watched the show and then came back a few minutes later and announced to his pupils that he had just joined the Organ Donor Register and produced a print out acknowledging his registration.



The Proper Pantomime Company engaging youngsters with their *Give Life* production.

“I was surprised how much some of the children already knew about transplantation. In one school there was only one child who hadn't heard about organ donation and transplantation and when I asked how many had seen the BBC *DoNation* season *Casualty/Holby City* special more than half the class put their hands up.”

The children were invited to take leaflets home to their families and encourage their parents and families to talk about their views on organ donation.

Melanie Edwards, National Sales Manager, Transplantation, for Astellas said: “Having attended two of these presentations by Chris' team at schools in Coventry I have been so impressed by these children's understanding of organ donation and their positive response to these workshops. Their creativity to broaden this understanding into their community has been inspiring.”

The production will tour schools in six areas in the spring term, including Cambridge, Surrey, Oxford and Plymouth.



Year 5 and 6 pupils in Oldham let their imaginations go with ideas for designing organ donation posters.

Politicians' views surveyed

In Spring 2005, just before the General Election, the National Kidney Federation (NKF) carried out a survey amongst all major party candidates to find out their views on renal issues.

The NKF posted three survey forms to 15,000 kidney patients and asked them to send these to each of their major parliamentary candidates. Out of the 1,950 candidates 968 unique replies were received: 473 from Labour, 272 from Conservative and 194 from Liberal Democrat candidates.

The survey asked about several issues. The following findings take into account only the positive responses indicating support (the most common replies to the questions being either "no response" or "other", rather than "no" indicating no support).

5% of the population are thought to be suffering from some form of kidney disease. Do you support existing plans (Renal National Service Framework) to find these patients and treat these patients at GP local level, in order to prevent further deterioration of kidney function?

- Labour 29%
- Conservative 33%
- Liberal Democrat 80%

Would you support an expansion of dialysis services to ensure that all patients who would benefit from dialysis are able to do so at a time and place convenient to them and with a full choice of suitable dialysis options available?

- Labour 28%
- Conservative 36%
- Liberal Democrat 80%

Would you support an increase in transplantation, an increase in the numbers of transplant surgeons and staff and resist the closure of transplant centres?

- Labour 27%
- Conservative 34%
- Liberal Democrat 80%

Which of the following initiatives would you endorse: (altruistic and pooled donation has already been included in new legislation)

altruistic living kidney donation between non-relatives?

- Labour 18%
- Conservative 19%
- Liberal Democrat 65%

pooled donation exchange between two or more "non-matched" tissue type couples?

- Labour 13%
- Conservative 14%
- Liberal Democrat 60%

elective ventilation and other clinical procedures to preserve organs prior to transplant?

- Labour 18%
- Conservative 17%
- Liberal Democrat 64%

fund and expand the transplant structure within the NHS?

- Labour 23%
- Conservative 31%
- Liberal Democrat 70%

support a change to presumed consent ie opt out rather than opt in system?

- Labour 16%
- Conservative 13%
- Liberal Democrat 64%

If elected would you become a member of the All Parliamentary Kidney Group of MPs and Lords?

- Labour 23%
- Conservative 32%
- Liberal Democrat 50%

Tim Statham, Chief Executive of NKF said: "We were pleased with the outcome of the survey which provided invaluable information about the opinions of individual candidates, some of whom are now elected members, and the general levels of support given by each political party.

"Another outcome has been the strengthening of the All Party Parliamentary Kidney Group and general awareness raising about renal disease amongst policy makers. In fact, following the election, the membership of the group rose from 108 to 174."

The full survey results can be found on NKF's website: www.kidney.org.uk/campaigns/Parliament



Credit: Free picture provided by London-GB.com

DoNation season gets millions talking

Final evaluation of the BBC's DoNation season showed that more than 80,000 people applied to join the NHS Organ Donor Register as a result of the programmes, while millions more were prompted to talk about donation with their loved ones.

Figures from UK Transplant found that 82,492 requests to register were received during the 27 days following the start of the season. The majority of applications – a total of 52,227 – were received online via UKT's website, while 20,721 were made via the Organ Donor Line and 9,994 through the interactive TV "red button".

Pre- and post-season surveys carried out by BBC audience and consumer research also revealed that large numbers were

prompted to talk about donation with a friend or relative as a result of seeing or reading about the programmes.

According to the BBC, one in ten people heard about DoNation on the radio or in the press, and more than seven million tuned in to watch the groundbreaking interactive episode of *Casualty at Holby City*.

This high level of awareness helped make donation a talking point, with the BBC estimating that more than five million discussed donation with a loved one as a direct result of seeing the programmes.

The number of people considering signing up to the register also increased over the course of the season, with figures showing a 3% rise in those who

said they were "very likely" to join in the next six months.

Meanwhile general awareness of the register, and of ways to sign up, also rose. When asked "How do you join the register?", 22% of respondents cited the UK Transplant website before the season, but afterwards the figure had risen to 29%.

Similarly, the number mentioning the Organ Donor Line rose from 16% to 18%, while 9% cited the "tick box" on the driver's licence application form, compared with just 2% before the season began.

The BBC's findings were based on a TNS representative sample of 2,067 adults questioned in May 2005, and 1,010 adults questioned in September 2005.

New black and Asian research

The National Kidney Research Fund is undertaking a new three-year study to address the serious shortage of organs donated from minority ethnic groups.

13% of people registered for a kidney transplant are Asian and 7% are black. However, amongst cadaveric kidney donors, only 1% are Asian and 0.8% are black.

The project, funded by a £203,000 grant from the Big Lottery Fund, and supported by the British Transplantation Society, will compare different attitudes about organ donation and transplantation among white, black and Asian communities in order to identify and overcome any perceived barriers to organ donation and, ultimately, improve organ donation rates within each group.

Participants for the study are being recruited from west London general practices. In-depth interviews will be carried out and the data will then be analysed to identify groups of issues.

Dr Anthony Warrens, lead investigator in the study, said: "By examining the cultural, ethnic and religious issues that

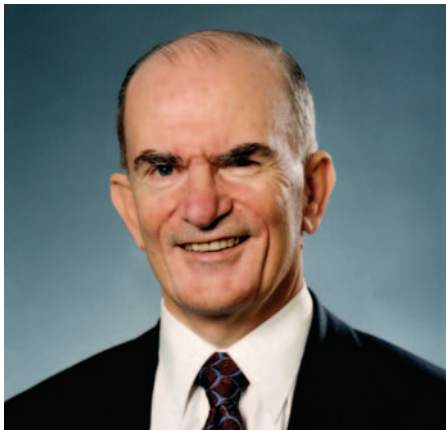
inform people's attitudes, we can use this knowledge to create more sensitive and cost-effective educational strategies that are culturally sensitive and can be individually tailored towards different communities."

UK Transplant is carrying out its own research in spring 2006 amongst South Asian and black communities. The findings will be used to inform our campaigns.

The research will aim to:

- benchmark current attitudes to organ donation
- create understanding of the communities' attitudes and barriers towards organ donation
- evaluate the effectiveness of existing communications
- ascertain which messages and channels are likely to be most effective in persuading target audiences to consider joining the ODR.





View from the chair

In May 2005 Bill Fullagar took up his new role as the first Chair of NHS Blood and Transplant (NHSBT).

Mr Fullagar, aged 66, has had a distinguished career and wide experience 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. With the merged organisation still in its infancy, we asked him about the challenges ahead.

What are the key strengths that you bring to your new role?

I have a long track record of managing large organisations, both in the UK and abroad, leading change successfully and I'm very used to dealing with mergers.

I've worked for many years in the pharmaceutical industry and I have had a lot to do with transplantation. I have worked with the NHS as a supplier: I know what it does and how it works.

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

I think my greatest success was when I was based in New York and I managed the merging of two pharmaceutical companies. The merger involved many thousands of people and, at the same time, I kept the business running effectively. Of course I had many people doing a lot of hard work with me.

What kinds of changes are in store for UKT and NBA?

The job in hand starts off with the job that would have been there if these organisations hadn't merged. These are

two organisations that over the past few years have established a good track record, but they, as other organisations, need to change.

My first impression is that both UKT and NBA are delivering well. The question is: to what extent do we need to change to keep abreast of changing circumstances and to what extent can we become more efficient?

In transplantation we still face the challenge of maximising the number of organs for transplant and meeting demand. UKT will be the first to accept that.

With blood we must continue to adjust to a changing environment with a decreasing demand for red blood cells and developments in the regulation requirements. I am fascinated by the change in demand patterns. You've got blood demand going down and the increasing challenge of retaining a loyal blood donor base.

It's premature to know what changes are in store. I don't yet know what the outcome of any long-term analysis will

be. But we mustn't lose sight of our priority of providing and improving services.

Within 6-8 months I would like to have plans on the table for all three operating divisions – UKT, NBS and BPL – so that everybody can see where we are going and start working towards the delivery of these new plans.

Will UKT retain its distinctiveness?

There's no intention of just squashing the NBS, UKT and BPL together.

Each does a very different job, and does it well, and we want each to retain their own identity and expertise. Some services will be offered centrally, to the benefit of all Operating Divisions.

How do you feel about the challenges ahead?

I'm excited. I'm not apprehensive. I'm excited on two counts: the job is more than interesting and the people I've met so far, and the team of directors we've brought on board, are good people – who are rightly proud of the job they do. There really is a lot to feel positive about.

NHSBT structure

NHSBT brings together BPL, NBS and UKT as three operating divisions. The prime focus of these three divisions will continue to be the management and supply of their own products and services to their own particular "customers".

The NHSBT team will define and set the strategy both for the organisation as a whole, and the NBS, BPL and UKT individually. Each operating division will be responsible for implementing the strategy. A number of services which support the delivery of products and services to customers, including HR, finance, IT and estates and facilities, will be provided centrally.

NHSBT is conducting a major review of strategy to be completed by March 2006. This coincides with the end of the strategic plans for NBA and UKT.

New board of NHSBT

The new board of NHS Blood and Transplant (NHSBT) consists of the chair, the chief executive, six non-executive directors and five executive directors. Martin Gorham was appointed as chief executive in July 2005 and the following appointments to the board (detailed below) have been made recently.

A further five NHSBT group directors will attend board meetings. The first two appointments of Director of Communication & Corporate Affairs and Director of Planning & Organisation Development have been made. Appointments are underway for three further NHSBT group director posts: Director of Human Resources, Director of Facilities & Estates and Director of Information Technology.

Bill Fullagar, Chair of NHSBT said: "I am delighted that we have been able to attract such a talented and skilled group of people to the new organisation. Between them they bring awareness of patients' needs, understanding as directors of UKT and the NBA, relevant knowledge of transplantation and haematology, and experience in managing complex organisations. I very much look forward to working with the new board to ensure NHSBT is in a strong position to face future challenges."

Non-executive directors



Elisabeth Buggins is chair of Birmingham and Black Country Strategic Health Authority and was a non-executive member of the National Blood Authority. Elisabeth is also a Director of engage2excel, a company specialising in patient and public involvement in the NHS.



John Forsythe is a consultant transplant surgeon and Clinical Director (renal/transplant surgery) at the Royal Infirmary of Edinburgh. He is chairman of the Scottish Transplant Group and a non-executive member for NHS Quality Improvements Scotland. He is also chair of UKT's Kidney and Pancreas Advisory Group.



David Greggains is a management accountant and director of a private company. He has experience of working in both the public and private sector and is a member of the Independent Monitoring Board for Harmondsworth Immigration Removal Centre.



Jennifer Gubbins is a practising solicitor and partner in Trowers & Hamblins and has been a member of the National Blood Authority since 1996 and vice chair since 2001. In her career in commercial law she has specialised in corporate finance, with a particular focus on the public

sector, and has worked with the NHS in setting up the NHS Litigation Authority.



George Jenkins is chair of East Kent Hospitals Trust and was a non-executive director of UK Transplant. He has held many non-executive and executive director roles in both the public and private sector. He is also chair of UKT's Patients' Forum.



Dr Diana Walford CBE is Principal of Mansfield College, Oxford and former Chief Executive of the Public Health Laboratory Service (PHLS). She was Deputy Chief Medical Officer of England between 1989 and 1992.

Executive directors of NHS Blood and Transplant



Martin Gorham – Chief Executive NHSBT

Martin has worked in the NHS for the whole of his career having joined as a national management trainee. He has run a number of hospitals, been Chief Executive of the London Ambulance Service, been Director of Projects and Corporate Affairs at NHS regional level and was appointed Chief Executive of the National Blood Authority in October 1998. He is President of the European Blood Alliance and also a trustee of the Princess Royal Trust for Carers.



Dr Angela Robinson – Medical Director NHSBT

Angela has been a consultant in the NHS since 1976, originally specialising in paediatric haemato/oncology and transfusion medicine. She was involved in the development of the first bone marrow transplant centre in Leeds. She became the Director of Yorkshire Blood Transfusion Service in 1988 and Medical Director of NBS in 1994. Angela has been the UK Government's designated transfusion medicine expert for both the Council of Europe and the European Commission for the last 10 years. She is also chair of the Council of Europe expert committee in transfusion medicine.



Barry Savery – Finance Director NHSBT

Barry joined the NHS in 1987 as Director of Finance for BPL. Prior to this, he worked in the private sector, holding financial and general management posts in the pharmaceutical, chemical and printing industries. He became the NBA's first Director of Finance when the Authority was formed in 1993 and held that position until the NBA was disbanded in September 2005.



Chris Rudge - Managing Director UK Transplant (UKT)

Chris was appointed UK Transplant's first Medical Director in 2001 to provide clinical leadership and has played a wide role in developing working relationships between UKT, the clinical transplant programmes in the UK and the critical care community. He was consultant transplant surgeon at Guy's Hospital and then St Peter's Hospital. In 1995 he became Director of Transplantation at The Royal London Hospital, where he continues to spend one day a week.

Peter Garwood – Managing Director National Blood Service (NBS)



Peter has worked with the National Blood Service for nearly 30 years. He trained as a biomedical scientist, working at King's College Hospital before moving to the Tooting Blood Centre in London in 1975. In 1994, he became Operations Director for the London and south east zone of the NBS. Peter was national NBS Director for Processing, Testing and Issue from 1999 until March 2004 when he was appointed as NBS Director of Service Delivery/Deputy CEO. From August 2005 he has acted as CEO/Managing Director of the National Blood Service.

Dr Clive Ronaldson – Acting Managing Director Bio Products Laboratory (BPL)



Clive is responsible for all the activities of BPL. His previous experience includes employment with Baxter Healthcare, a US multi-national, from 1976 to 1993 where he became factory manager in the UK. He joined BPL in 1993 to take responsibility for manufacturing and associated activities.

NHSBT group directors

Terry Male – Director of Planning and Organisation Development NHSBT



Terry joined the NHS in 1975 and trained as a biomedical scientist before joining Life Sciences International as R&D Manager in 1986. From here he moved into business development and joined the Yorkshire Regional Health Authority as Organisation Development Specialist. Terry joined the Blood Service in 1993, becoming the Operations Director for the northern zone and then NBA Transition Director in the move to a national service. In 2004 he became Director of Corporate and Workforce Development for the NBA.

Liz Reynolds – Director of Communication and Corporate Affairs NHSBT



Liz has worked for the NBS for nine years as Director of Public and Customer Services, establishing its professional marketing and communication credentials. Prior to this, Liz worked in the commercial sector including working for Sears plc leading business-wide change programmes and Kingfisher plc in a marketing strategy role for Comet. She is also a non-executive director and trustee for Traidcraft.

Women students playing online game



Organ-ise, the groundbreaking student on-line game, has attracted more than 10,000 entries to win the retro game Operation, as students vie to complete a record number of transplants.

An early analysis of players shows that women are bucking the trend of internet games, and out-number men in taking part. Also, students in Scotland are playing the game more than their English and Welsh counterparts.

The campaign is a new initiative from UKT to capitalise on the rapid spread of awareness gained from using connections on the web.

The site offers key information and statistics about organ transplantation issues as the game loads. Two links are permanently on display to encourage players to join the ODR via the UKT website. Visit www.organ-ise.org.uk to learn more.

Rugby players at a Bristol school will be touching down to help spread the message about organ donation and transplantation.

The team of Year 11/12 players from St Mary Redcliffe and Temple School kicked off the season sporting new kit sponsored by UKT.



St Mary Redcliffe and Temple head of PE Dave Boddy said: "The school prides itself on its caring ethos and helping to spread the message about organ donation is part of that. As well as building a positive team spirit, we hope this new kit will encourage our players, our opponents and spectators to think about the issue of organ donation."

First UK living liver transplants set to start in Scotland

The first living liver transplants between adults in the UK will begin in April 2006 in Scotland. This is the first time that this treatment will be available to patients on the NHS and, with Scotland pioneering the way, it is expected that transplant surgeons will be pressing the NHS in England and Wales to follow suit.

Living liver transplants are already carried out in other countries including the USA, Japan, Germany and France. In addition, these operations have already been successfully carried out on the NHS between adults and children and have been performed privately between adults from outside the UK at London's King's College Hospital.

The operations in Scotland will be carried out at the Edinburgh Royal Infirmary (ERI) transplant unit.

Scottish Health Minister Andy Kerr said: "I welcome the fact that patients across Scotland and their families will have the option of considering this form of transplantation."

Consultant Surgeon John Forsythe, Clinical Director at ERI Transplant Unit, commented: "In the Scottish Liver Transplant Unit we are delighted that this programme is being made available for those suffering from liver failure. Year by year the number of patients who die whilst waiting for a liver transplant is increasing.

"The surgery itself is quite daunting because operating on a living donor is so different to any other procedure which we do. Clearly, and fundamental to this approach, it is very important to us that any potential donor fully understands the risks and benefits."

Maureen Cunningham, transplant

co-ordinator and member of the donor advocacy team, said: "Every potential donor will have to be fully assessed to ensure they are suitable and that they are not acting under any kind of coercion, whether emotional or financial.

"Once approved, a donor will need a lot of support and advice leading up to, and following, the transplant procedure. This aspect of care is new but we are excited that we are moving into this area of transplant surgery. We have been learning from world experts in this field and have adapted them to work within the NHS."

The liver is an unusual organ since, when part of it is removed, it can regenerate. Therefore the right lobe can be removed and transplanted into a recipient, and this is followed by regeneration in both the recipient and the donor so that the liver has the potential to grow to full size in both patients.

The number of patients to fit the indications for the programme will be around 50, but once all other factors have been taken into account, including those who receive a new liver from a cadaveric donor, it is likely that there will be around five procedures in the first year, 10 in the second year of the programme and 15 in following years. As patients and families become more aware of the possibility of living donor liver transplantation, it is likely that the programme will expand.

In the initial phase of the programme, the procedure will be limited to those suffering from chronic hepatic failure. Those who suffer from acute liver failure have only a few days to live and it is felt that this short time scale may give rise to errors in the assessment

process during the early phase of the programme. In its early stages, only those patients who would normally be listed on the conventional liver transplant list will be considered for the programme.

For living liver donation, the risk of death is somewhere between 0.5 and 1 percent, according to results reported from centres around the world. The risk of complications is around 20 percent, which means that there is a one in five chance that the donor will experience problems after donation. This compares with a risk of death of 1 in 3,000 for living donor kidney transplantation, and a complication rate of about 1 percent.

In line with current recommendations, the assessment of the intended liver donor will be performed by a team consisting of all the health professionals qualified to comment on every aspect of the welfare of the intended donor and to provide a safe system for the evaluation of the suitability of the donor to proceed to donation. All donors will be seen by an independent medical assessor, who will be independent of the transplant unit.

The donor must be an adult (over the age of 16) and must have the capacity to provide valid consent in legal terms. The potential donor will be given a minimum period of 24 hours of reflection to ensure that their decision to donate has been fully considered, and to allow time for discussion with family members.

These procedures will be amended to take account of any further requirements, which the Human Tissue Authority may introduce once its procedures are put into place, which is expected to be shortly after the commencement of the programme.

NBS tissue services programme

Tissue Services is a function within the NBS operating division of NHSBT. The staff work closely with families, hospitals, other health professionals and other services to raise awareness of tissue donation and maintain the highest standards in this life-saving and life-enhancing field.

Professor John Kearney, Head of Tissue Services, describes the work of the tissue donation and banking programme.

Collection

Tissue can be donated from both living and deceased donors.

Living donors can donate bone, removed at the time of hip replacement surgery and amnion, the foetal membrane expelled with the placenta, retrieved following caesarean section.

Deceased donors can donate bone, heart valves, tendons, corneas and skin.

A National Referral Centre is based in Liverpool at a brand new multi-million pound facility that opened in July this year. From here, teams of two or three specially trained practitioners respond to requests for tissue retrieval from hospitals all over England and North Wales.

Nurse practitioners at the centre respond to deceased donor referrals during office hours and a team of 19 whole time equivalent tissue donor co-ordinators, based at hospitals, work with a wide variety of professional groups to establish and maintain donor referral programmes.

Preparation of the clinical allografts (tissues from human donors destined for transplantation) is carried out in centres in both Liverpool and London.

Production and tissue banking

Each year we provide over 7,500 grafts for transplant to over 300 UK hospitals.

Tissue banking has a great deal in common with blood banking in terms of practice, procedure, standards and quality management.

Once a deceased donor is referred, a technical team is sent out to the hospital to retrieve the tissues from the mortuary within 36 hours of death, a process taking up to three hours. An important part of the retrieval process is to afford appropriate respect to the donor and to reconstruct the body following tissue retrieval. Once retrieved the tissues are brought back to the bank.

There is an array of checking procedures that we must carry out before tissues can be banked. This includes carrying out a series of tests on the tissues and checking the medical



All tissue processing has to be carried out in specialist cleanrooms with sterile filtered air.

history of the donor through medical records and information from GPs and the next of kin.

All tissue processing has to be carried out in specialist cleanrooms with sterile filtered air. Some tissues are processed within 24 hours of retrieval to maintain their viability and/or structure whilst in storage. These include skin, heart valves, amnion and cartilage grafts. Following careful dissection, shaping and antibiotic treatment, a cryoprotectant is added and the tissue is slowly cooled to below -135°C .

Other tissues, including bone and tendons, can be frozen in a -80°C mechanical freezer. These tissues are then shaped in cleanrooms before undergoing chemical disinfection.

Tissues can be frozen or freeze-dried and most tissues are sterilised by irradiation.

Research and development

R&D is very important to the development of tissue banking and with our new state of the art centre in Liverpool we can carry out R&D on site for the first time. The Tissue Development Laboratory will be working alongside the routine tissue processing facility, giving direct interaction and collaboration and allowing us to apply new technologies to tissue grafts.

We also have a programme of new product development. Many of these developments arise out of our research programme. Within the field of tissue engineering we can modify tissue grafts to make them more compatible to the recipient, for example by removing the donor cells and replacing them with recipient cells.

Research is funded by competitive grants and most of it is carried out in collaboration with universities and is conducted in university laboratories.

Regulation and Legislation

Legislation that previously controlled aspects of tissue banking included the Human Tissue Act 1961, the Anatomy Act 1984, and the Human Organ Transplants Act 1989. Regulation via a voluntary "Code of Practice for Tissue Banks" was introduced in 2001, with the Medicines and Healthcare Regulatory Authority (MHRA) as the inspectorate. There are now, however, major changes that will come into force in the near future.

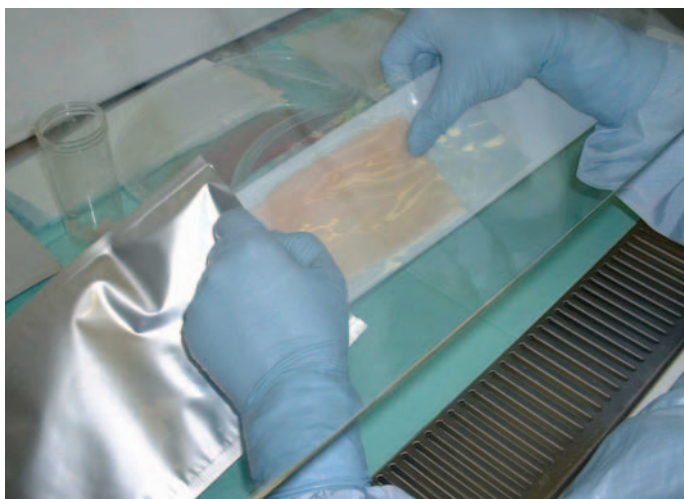
- Human Tissue Act 2004 – repeals and replaces the previous three acts. The emphasis in the Act is on obtaining appropriate consent to undertake specified activities including removal, storage and use of human tissue for transplantation and research.

The act also establishes the Human Tissue Authority (HTA) to advise on, and oversee compliance with, the Act. The authority has recently issued five codes of practice and one regulation for consultation. Tissue banks will need to comply with the relevant sections of these documents.

- EU Tissues and Cells Directive (2004/23/EC) – from April 2006 the HTA will be the competent authority under the European Directive. Compliance with this Directive will be a legal requirement, replacing the current voluntary Code of Practice administered by the MHRA.
- Tissue Engineering Regulation – the EU is currently drafting a "Regulation" for tissue-engineered products; which would therefore be regulated differently to tissue banked products. This new legislative and regulatory environment is posing a significant challenge to tissue banking. It will cover both public and commercial sector activity where there was previously no adequate legislation.

Skin

NBS Tissue Services provides almost all the UK allograft skin requirements for patients with life-threatening burns. Skin, however, is in short supply and, in addition, we plan to build contingent stocks for emergencies.



Skin can be used as a life-saving treatment for severe burns victims.

The demand for skin over the last five years has increased dramatically as the benefits of this life-saving treatment have been realised.

To build up enough stocks we need to maximise the existing donor pool. Our tissue co-ordinator nurses have traditionally looked for tissue donors independently of the organ donation programme and currently very few organ donors donate skin.

We hope that through working more closely with UKT, there should be an opportunity to increase awareness of the need for skin.

Other ways of increasing stocks will be through application of sterilisation techniques to non-sterile skin, and investigating the potential for import.

vCJD

Some tissues, like blood and organs, are life-saving eg skin for burns. However most tissues are used in greatly life-enhancing surgery eg bone for hip revision. As a result patients consenting to these procedures (and surgeons doing them) need to weigh the risk (including disease transmission) against benefit.



Bone can be donated from both living and deceased donors.

There have been two probable cases of vCJD transmission by blood transfusion in the UK. We therefore presume there is also a non-quantifiable risk of vCJD transmission by tissue transplant.

As part of risk reduction Tissue Services are looking to improve processing techniques, to increase awareness amongst users and we are looking at the potential for import from countries where vCJD doesn't exist (particularly for children born after 1996 who have not been exposed to the risk of vCJD in the food chain). We are also evaluating routine testing of deceased donors for vCJD.

Against all these unknowns, Tissue Services have also drafted a NHS UK-wide tissue transplant patient leaflet to be used by health professionals to help patients in their choice to have surgery.

Will Hepatitis C overwhelm the liver transplant programme?

With reports that there could be as many as 500,000 people in the UK infected with the hepatitis C virus, James Neuberger, Professor of Hepatology at Queen Elizabeth Hospital Birmingham, considers the effect this could have on liver transplantation.

In the UK, transplant activity is severely limited by the availability of donor organs. Despite initiatives sponsored by UK Transplant and other organisations, the number of donor livers available for liver transplantation has in recent years remained broadly static.

The greater use of split livers and better definition of the marginal liver has had a significant although small impact on increasing the effective number of organs available. Other initiatives such as the use of livers from non-heartbeating donors will further increase the number of livers available but the extent of this increase is likely to be relatively minor.

Living donor transplantation, with all its ethical and other issues, is now being actively considered for introduction in England and Wales, and will shortly be introduced in Scotland. In some countries such as Japan, the great majority of liver transplants are done using living donors whereas in other countries such as the United States, living donation has a relatively modest impact on the number of transplants.

The lack of livers for transplantation means that many patients with end stage liver disease who might have benefited from a liver transplant are denied access to this option. Indeed, of those patients who do meet the current criteria for liver transplantation and fulfil the criteria for benefit (the 50% five-year rule agreed in Edinburgh in 1999), there remains a significant morbidity and mortality. This morbidity and mortality appears to be increasing.

The trend of liver transplantation in the UK is, broadly speaking, similar to that seen in continental Europe and the United States. We are seeing an increase in the numbers of patients transplanted for end stage liver disease associated

Recent media coverage has highlighted a "hidden epidemic" of hepatitis C.



with alcohol and hepatitis C viral infection (HCV) and sometimes with a combination of both.

Given the increasing number of people with obesity in the UK population, it may be that some of these patients will develop end stage non-alcoholic steatosis and hepatitis and so become transplant candidates in time. Thus the pressures for transplantation will continue to increase and, against what is at best a static pool of donors, the pressures will continue to increase.

Recent media coverage has highlighted a "hidden epidemic" of hepatitis C and suggested that 500,000 people in the UK carry the virus, nine out of ten being unaware of their infection. What effect will this have on the liver transplant programme?

Certainly, we are seeing an increase in the number of patients transplanted for end stage hepatitis C. In the last five years there have been 507 liver transplants in the UK for patients with post hepatitis C cirrhosis (14.1% of all liver transplants) whereas for the previous five years the figure was 409 (11.8%).

It must, however, be emphasised that for many people with hepatitis C, transplantation is not indicated. Many, for example, have relatively mild disease and would not benefit from transplantation. Others might be contra-indicated for transplantation because of coexisting extra-hepatic disease.

Furthermore, the great advances made in the treatment of hepatitis C have made predictions of the number of those who will come to end stage liver disease relatively inaccurate. We are already seeing, with the use of Pegylated Interferon and Ribavirin, cures in a significant number of people with hepatitis C viral disease, a phenomenon that would not have been considered, even ten years ago.

There are currently many other types of anti-viral treatments being evaluated and developed and it remains uncertain the extent to which introduction of novel agents and approaches will reduce the burden of hepatitis C in the general population. One of the current concerns for liver transplantation for hepatitis C is the inevitable recurrence of disease. In almost every case, hepatitis C will infect the graft (which is commonly known as re-infection) and, to a variable extent, this will lead to progressive graft hepatitis cirrhosis and graft failure.

Current data suggest that longer-term survival of patient and graft is lower for those grafted for HCV infection, in part due to graft infection. Cirrhosis will develop in around 30% at five years. A small number will develop another form of graft damage, fibrosing cholestatic hepatitis.

A number of factors are known to be associated with the rate of graft damage. Amongst these are the age of the donor, the number of episodes of acute rejection, the use of immunosuppressive agents and the titre of hepatitis C at the time of transplantation. In those with graft failure, re-graft is the only therapeutic option. Outcomes of re-graft have been variable; in the past many patients were grafted when they were so sick that the outcome was poor.

Approaches to reduce the toll of hepatitis C graft infection have been underway for some years. One approach has been to treat the patient with low and accelerating doses of drugs. The aim of this approach is to reduce viral replication to zero prior to transplant as this has been associated with much less graft damage. A second approach is to intervene post-transplant with either pre-emptive treatment or to offer treatment to those with early and developing fibrosis.

Data remain preliminary. Treatment is expensive and burdensome to the patient since many of the effects of Interferon and Ribavirin appear to be exacerbated in the allograft recipient and response rates are relatively poor. Nonetheless, the increasing expertise in the use of anti-viral agents, better use of immunosuppression and the potential introduction of new agents (anti-viral, anti-fibrotic or different immunosuppression agents) are likely to improve the outcome over the next few years.

Predictions for the future are often unreliable since the impact of new technologies is hard to forecast accurately. Nonetheless, the number of people grafted for end stage

- **Hepatitis C is a viral infection of the liver. The virus is primarily spread by direct contact with blood.**
- **In England the most common route of infection is through injecting drug users sharing contaminated needles.**
- **Most people who become infected are not aware of it at the time. Those with chronic infection may have no symptoms, which is why hepatitis C is known as the silent epidemic.**
- **Just over 14% of liver transplants in England are undertaken because of liver damage caused by chronic hepatitis C infection.**
- **The World Health Organisation estimates that globally 170 million (3% of the population) are chronically infected with hepatitis C and that 3–4 million people are newly infected each year.**
- **A recent report published by the Hepatitis C Trust *Losing the Fight Against Hepatitis C* said that the UK was at the bottom of the league on treatment, with fewer than 2% of cases receiving drugs compared to 15% in France.**

hepatitis C is likely to increase, at least in the short term and this will lead to a cohort of patients who will develop graft failure within five to ten years of transplantation.

Re-graft is certainly an option and for many people this is highly effective in increasing survival. Yet in the context of what is likely to be an ever increasing shortage of organs, development of an increasing number of people requiring a re-graft who will compete with an increasing number of patients who require a primary graft, this will cause stresses and strains within the system.

In theory, the way forward is clear: hopefully, the public health strategies already in place will reduce the number of new infections and better recognition of those patients with hepatitis C infection will allow earlier treatment and so reduce the burden of those with end stage disease who require transplantation.

In the short to medium term, however, a major significant number of people with hepatitis C are likely to require not only one transplant but, despite treatment and interventions, two or even three transplants to allow them to return to a normal healthy and productive life.

The challenge is on the clinicians and scientists to develop effective therapies for hepatitis C and on the general public to provide enough donor livers for those in whom treatment is ineffective.

Cardiothoracic Advisory Group

CTAG met on 7 September 2005

- An informal review of the criteria used in listing patients for transplants at different centres identified no major differences in current practice. A formal review will therefore not be necessary.
- Initial work has taken place on a process for Histocompatibility & Immunogenetics laboratories to work together to deal with the 10-25% of patients who are sensitised to HLA antigens. More data is needed to allow the group to assess the extent of the problem and the potential benefit from the proposal.
- A programme of Donor Care Physiologists (DCPs), which was piloted at Papworth Hospital will allow greater compliance of junior doctors with the European Working Time Directive and will substitute the anaesthetist's role during the multi-organ retrieval procedure. In the future it is hoped to roll this programme out to other centres.
- Agreement was reached on a joint proposal between the Royal College of Surgeons Clinical Effectiveness Unit (RCS CEU) and UK Transplant (UKT) for the future provision of the UK National Cardiothoracic Transplant Audit. The National Specialist Commissioning Advisory Group (NSCAG) has accepted the draft funding proposal and is awaiting a formal joint proposal.
- Evidence from the national Potential Donor Audit (PDA) for 2004 suggests that there are significant differences in the proportion of potential donors becoming actual donors across the cardiothoracic zones. The 21-month summary report of the PDA is available on the UKT website.
- Draft standards for living donor lung transplantation within the UK were proposed. The Human Tissue Authority codes of practice on living donation together with international guidelines on living donor lung transplantation will need to be considered when finalising UK national standards. The current UK Transplant living donor registry for kidney donors will be expanded to incorporate non-renal living donors to form a national living donor registry.
- Recommendations for a national standard of practice were made following investigations into an incident where a patient with preformed antibodies inadvertently received a lung transplant from a donor with an HLA antigen to which the patient was sensitised. These recommendations will be circulated to all cardiothoracic transplant centres and H & I laboratories together with an explanatory letter reinforcing details of the UKT forms and referring to the guidelines for the detection and characterisation of clinically relevant antibodies in solid organ transplantation, which are available on the British Transplantation Society website.
- The revised National Heart and Lung Transplant Standards were endorsed subject to minor amendments. Following comment from relevant organisations and NSCAG the document will be issued to each cardiothoracic transplant centre for completion of self-assessment prior to NSCAG visits. The standards will also be placed on the NSCAG website as well as being accessible via a link on the UKT website.

- The limit on the number of adult urgent registrations permitted per centre will be based on 30% of the number of heart transplants carried out by each centre during the previous financial year. Also, each centre is expected to payback with the next heart that becomes available. Any centre donating an urgent heart to Great Ormond Street will be deemed to have satisfied its payback to the system as a whole. Great Ormond Street will continue not to be required to payback as it does not have a zone.
- An urgent heart allocation scheme (UHAS) listing of a previously registered non-urgent patient will be accompanied by supplementary, full, secondary clinical registration form completion to allow more detailed prospective audit of the UHAS. The existing exclusion criteria will continue to be used with the addition of the proposed generic inclusion criteria. Centres wishing to register any other patients should send justification in writing to the CTAG Chairman.
- There are problems with managing the expanding lung transplant list within the Manchester area despite strict acceptance and assessment criteria. Work is to be undertaken to establish the causes for the high rate of the non-retrieval of lungs in the Manchester area and on why the donor rates are much higher in the Birmingham area. An interim arrangement was agreed for one year only whereby Manchester has first refusal on lungs exported from the northern part of the Birmingham zone. Also work is to be undertaken to compare potential lung donor differences across zones.
- The current criterion for registering small adult patients as paediatric is 40 kilos or less in weight. On occasions when a height criterion is required the matter should be referred to the CTAG Chairman for a decision.
- A policy of ensuring that during multi-organ retrievals, when heart and lungs are being sent to separate centres, the heart is packed and despatched prior to the removal of the lungs was recommended for adoption as a national standard.

Transplant Co-ordinators Advisory Group

TCAG met on 28 September 2005

- An amendment has been made to the tissue donor information form to reflect the fact that the family has given consent to disposal in accordance with hospital policy. It is the responsibility of each trust to establish a disposal policy.
- It will be a requirement under the Human Tissue Act to access the NHS Organ Donor Register (ODR) when considering donation requests. There was an 87% increase on the last quarter in requests to access the ODR by health care professionals.
- Four workshops took place as part of the consultation on the HTA codes of practice. Training will take place for UK Transplant staff and co-ordinators on the impact of the Act and implementation of the codes of practice and on how to communicate the changes to the intensive care community.

The final codes of practice are due to be laid before Parliament in early January with an anticipated implementation date of 1 April 2006.

- There has been an improvement in both the approach rate and the relative refusal rate in the last nine months of the Potential Donor Audit with the average refusal rate now around 40%.
- The knowledge and skills framework (KSF) outline for donor co-ordinators and team leaders has been compiled.
- A new advisory group will be established to offer advice to UKT on donor issues and to develop the relationship between UKT and the critical care clinical community. This will include representatives from tissue co-ordinator services and replace the existing TCAG.
- The final consultation on the proposals from the Working Party on Codes of Practice for Diagnosis of Brain Stem Death is due to take place in February 2006.

Pancreas Task Force

PTF met on 21 October 2005

- NSCAG will not be commissioning islet transplantation for the foreseeable future, in part due to the uncertainty of data on long-term outcomes.
- Sensitised patients may be listed at UKT for a kidney transplant at one centre whilst being registered locally for a kidney/pancreas transplant at a second centre.
- Consent for donation should be obtained in relation to the intended use of the donated pancreas. If the intention is to use the organ for clinical treatment, including the isolation of islets with the intention of using the islets for treatment of a patient under a clinical trial, then consent for research is not required. In situations where the pancreas retrieval is solely for the purpose of laboratory research then consent for research must be obtained.
- The retrieving centre will have first refusal to carry out local pancreas transplantation, with or without a simultaneous kidney transplant, prior to exporting the pancreas. All centres will have priority for use of the pancreas as a solid organ transplant before the pancreas is made available for islets. Each centre offered the pancreas would have the option of using it for either a solitary pancreas transplant or in combination with a kidney.
- There should be no difference in the liver perfusion method between a non-heartbeating donor and a heartbeating donor, although in practice this might not be the case due to perceived anxieties about livers from non-heartbeating donors. When retrieving liver and pancreas the portal vein should not be perfused, although when retrieving liver only this is acceptable.
- A proposal for a pilot scheme to share organs for sensitised patients between Oxford and Cambridge was agreed following discussion on the establishment of a national priority allocation scheme for sensitised patients and the impact this might have on the current sharing scheme. A proposal for a joint scheme between Edinburgh and Newcastle will also be drawn up. The pilot will not affect the UKT Duty Office systems as these will be locally retained pancreata and only for patients with sensitised antibodies.
- There is no evidence to suggest that kidney graft survival is inconsistent between simultaneous pancreas and kidney (SPK) and kidney only (KO) transplants, however there is evidence that patient survival for SPK transplants is inferior. There is insufficient data to merit a change to the guidelines on performing pancreas transplants on recipients over the age of 50. The principle of monitoring recipient fitness should be adhered to with age as an influencing factor.
- The Pancreas Task Force had previously agreed that when there is more than one potential '000' mismatched paediatric and '000' mismatched highly-sensitised adult patient then simultaneous kidney and pancreas (SPK) offers should be withdrawn. However, for paediatric donors the kidney offering principles state that all suitable paediatric recipients need to be considered ahead of any matched adult patient. Therefore all paediatrics will now be offered kidneys ahead of '000' highly sensitised adults. Also, all paediatric recipients and '000' mis-matched highly sensitised adults will take priority ahead of any proposed SPK recipients.
- As the proposed new kidney allocation scheme currently stands, the offer of a kidney to accompany the pancreas will occur after kidneys have been offered to recipients eligible in levels 1 and 2 of the new scheme.
- Following a report on pancreas retrieval activity the zones will remain as at present with pancreas zonal teams increasing efforts to retrieve pancreata deemed suitable for transplant.
- A system was agreed of advance warning of an offer of a potential pancreas donor as soon as it is declared that the designated retrieval unit are unable to retrieve. The time slot for acceptance will be one hour and the accepting unit will be obliged to retrieve the pancreas. Any centres not responding will be deemed to have declined the offer and if more than one centre accepts the offer the donor will be allocated according to the balance of exchange at that time. Details of the changes to the offering process and how to record such instances in the balance of exchange will be reviewed at UKT and confirmation circulated to centres prior to implementation.
- Access to training for pancreas retrieval was discussed and work on establishing a cadaveric laboratory in Newcastle was welcomed. Pancreata will continue to be offered to every centre even when other centres have refused the organ, the only exception being when the retrieving surgeon specifically states that it would not be suitable for donation.

OTAG clarification

We would like to clarify a point made in the report from the Ocular Tissue Advisory Group meeting on 29 June 2005. Routine testing of all eye donors for HTLV is mandatory. However, if an exceptional occasion were to arise whereby fresh ocular tissue needed to be transplanted in circumstances where the HTLV result is not yet available, then it may be appropriate to consider proceeding with the transplant if clinically justified.

New post in Manchester to raise community awareness

Central Manchester and Manchester Children's University Hospitals NHS Trust have received funding to create an exciting new post based in the north west. The main aim of the post will be to reverse the current refusal rate. The post is the very first of its kind, and will be geared towards community awareness.

The post holder will need to work closely with transplant co-ordinators, the trust PR department and UK Transplant, as well as forging contacts with the local media. The post holder will also have a pivotal role in making sure that the north west is active in raising awareness at peak periods throughout the year, such as National Transplant Week.

Neil Parrott, Consultant Surgeon at Manchester Royal Infirmary is co-ordinating the development of the post. He said: "The objective is to see if we can reverse the 40% relative refusal rate that is seen, not just in the north west, but across the UK. On balance, I think this post needs someone with PR and marketing skills rather more than medical skills, and they will need a very thorough induction about transplantation and donation. I hope that this will move forward in 2006. Watch this space with interest!"

Tracey Dudley has won the **Award for Excellence in Transplant Nursing**, from the International Transplant Nurse Society, after being nominated secretly by colleagues.



Tracey Dudley wins international transplant nursing award.

Tracey has worked in liver transplantation and organ donation at the Queen Elizabeth Hospital in Birmingham for almost 16 years. Her roles have included sister in the liver transplant unit and donor transplant co-ordinator. Her current role is post-transplant hepatitis clinical nurse specialist for liver transplant recipients.

One of the benefits of winning the award is the chance to go to another part of the world to study. Tracey plans to go to a transplant centre in the USA to look at the management of patients receiving treatment for recurrent hepatitis C after liver transplantation.

Armed with the knowledge that their expenses forms had been correctly filed, West of Scotland transplant co-ordinators, William Murray and Ros O'Sullivan, joined the National Kidney Research Fund (NKRF) at a **donor awareness day at Centre One**, the HM Revenue and Customs based in East Kilbride.

Centre One staff were able to find out about organ donation and pick up a donor registration form at the awareness event – which produced 250 registrations.

Two hundred relatives remembered and celebrated the generosity of their loved ones' life-saving donation of organs or tissue for transplant at a **special "gift of life" thanksgiving service**.

Families whose loved ones donated organs or tissue for transplant during the past five years joined together at the thanksgiving service in October.

The Reverend Nick Flood, chaplain at the Royal Hampshire County Hospital in Winchester, conducted the service and several family members spoke of their experiences.

Transplant co-ordinator at Portsmouth and organiser of the service, Alison Hansford, said: "Each of these families has had the experience of losing a loved one – but they selflessly decided that something good should come from their loss, something that will save or enhance the lives of others."



The eye retrieval team at the Royal Victoria Infirmary in Newcastle hit upon the idea of using **specially designed carrier bags** to promote the cornea donation message.

The bags, being sponsored by UK Transplant as a pilot, are being launched at a special event at the hospital to celebrate the 100th centenary of the first successful cornea transplant.

The bags will be used by the hospital pharmacy and will also be used by the retrieval team in their awareness raising work.

Consultant ophthalmologist, Francisco Figueiredo, said: "We're hoping that people will literally carry the message about cornea donation with these bags. We think the design is simple but striking and we have all kinds of ideas about how we could use them within the hospital."