

# bulletin

**NHS**

*Blood and Transplant*

The newsletter for everyone involved in organ transplantation and donation  
Issue 64 Autumn/Winter 2007

**In this issue:** The UK's first paired kidney swap and adult to adult living liver donor transplants. Donor Register mailing to millions of UK homes. UK team scoops 100 gold medals at World Transplant Games. Transplant co-ordinators awarded St John Ambulance Fellowship. Appointment with Dr Martin Smith.



It is expected that the Health Departments' Taskforce report will be made public very shortly. The terms of reference of the Taskforce were simply to identify obstacles to increasing organ donation and to recommend solutions. There is really no limit to the increase in donation that might be desirable, but realistically a 50% increase would be a notable achievement and would bring the UK's donor rate more closely into line with other western European countries (with the glaring exception of Spain). A 50% increase would mean that each year there would be over 700 more kidneys for transplantation, over 300 more livers and 60-80 more hearts and lungs.



A critical aspect of this – outside the remit of the Taskforce but clearly recognised nonetheless – is that there will be a need for increased resources within transplant units themselves. More beds, more operating time, more staff and more specialist support such as the histocompatibility laboratory services will all be needed and it would be absurd and tragic if limitations in these areas led to organs – and lives – being wasted.

Specialist commissioners, at both national and local levels, will need to respond if the recommendations are implemented and are successful. The increase in donation will not happen suddenly but should be apparent within 2-3 years and could reach its full effect within 5 years.

There is a broad consensus that at present some, if not all, transplant units could increase the number of transplants that they perform relatively easily, but I suspect that a major increase as I have described above could not be sustained without expansion. It is probably unfair and wrong to single out one discipline

because transplantation needs such a wide range of skills and expertise, but the shortage of transplant surgeons has been a cause for concern for many years and it is still not possible to do transplants without surgeons. The difficulties of attracting trainees into transplant surgery and establishing attractive and satisfying consultant posts have received attention from many quarters, most particularly the British Transplantation Society. In many ways things are somewhat better now than for some time, as the size and enthusiasm of the Carrel Club testify. The larger transplant units – particularly those that carry out both liver and kidney or kidney and pancreas transplantation – have in general been more successful in attracting and retaining the next generation of transplant surgeons. But some of the kidney-only units have had more difficulties and with the changing pattern of cardiac surgery in general, there are real anxieties about the future for heart and lung transplantation.

There is something of the “chicken and egg” problem here, too. It is much easier to make the case for more resources when the workload has increased than it is to plan ahead for an expected increase in donation and transplantation. But I am firmly of the opinion that now is the time for the British Transplantation Society, the Royal Colleges, commissioners and others to be looking very seriously indeed at the infrastructure within transplant units and at the resources – surgical staffing in particular - that will be required to plan for the increase in donation and transplantation that I believe is entirely achievable if the Taskforce recommendations are implemented.

Chris Rudge  
Managing & Transplant Director – UK Transplant

# bulletin

IS PUBLISHED QUARTERLY ISSN 1472-0507  
Copy date for Spring 2008 edition 31 Jan 2008  
Contributions should be sent to Henny Fordham

UK Transplant, Fox Den Road, Stoke Gifford, BRISTOL BS34 8RR  
Tel: 0117 975 7562

Fax: 0117 975 7515 Email: [bulletin@uktransplant.nhs.uk](mailto:bulletin@uktransplant.nhs.uk)

Designed by Bob Design and Marketing [www.meetbob.co.uk](http://www.meetbob.co.uk)

*Front cover picture:*

*Patrick Hayes 14-year-old double-lung transplant recipient, see opposite page*

### Copyright and Liability

2007 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](http://www.uktransplant.org.uk)

## Coming soon through a letterbox near you...

**Millions of householders have started receiving a direct appeal to join the NHS Organ Donor Register (ODR) to help tackle the chronic shortage of donated organs.**

The mass mail drop will hit 11.6 million homes – reaching virtually half the UK population – over five months as part of UK Transplant's My life, My gift campaign that aims to boost the numbers of lives saved and transformed each year through organ transplants.

The high-profile campaign, bringing hope to the 9,000-plus people currently needing an organ transplant, kicked off in London on 1 October. The special leaflet contains basic facts about organ donation as well as a Freepost form for those wanting to join the ODR. It also includes a personal call to action from Chris Rudge, UK Transplant Managing and Transplant Director.

"Research over many years has shown that the vast majority of people support organ donation – and that the main reason more have not acted on that support is that it is something they have not got around to doing or were not sure how," said Chris.

"By launching this direct appeal into millions of homes, we are therefore encouraging many more people to take that simple but vital next step of registering their wish to become an organ donor – and telling their families."

The plea to help is echoed by Patrick Hayes from Chiswick, whose 14-year-old son - also Patrick – underwent a double lung transplant at London's Great Ormond Street Hospital in March.

"The change in him since his transplant is incredible – he's back at school full time, has taken up cycling and running and on holiday in Ireland in the summer he was running up and down steps in all the castles we visited.

"He was only on the transplant list for three weeks before we got the call, but in that time he had deteriorated so fast



**Message of hope: 14-year-old double-lung transplant recipient Patrick Hayes and Hope Street resident Charlie Smith back UK Transplant's My life, My gift leaflet campaign that urges London's 3.1 million households to join the NHS Organ Donor Register.**

– he couldn't even bend down to tie his shoes and was on 100% oxygen. We are so grateful to the anonymous donor and their family as without them I don't think Patrick would be here today."

For people wanting to find out more about organ donation and transplantation before making their decision, the leaflet also contains details of a website [www.mylifemygift.org](http://www.mylifemygift.org) and the Organ Donor Line (0845 60 60 400) – which can also be used to join the ODR.

"For every person receiving the leaflet, there are three ways for them to offer real hope to more than 9,000 people currently waiting for the gift of life that a transplant will bring them," added Chris Rudge.

The London Campaign was due to reach all 3.1 million households in the capital's 33 boroughs but unfortunately the mass mail out coincided with the postal strike. Urgent contingency plans had to be made to distribute the remaining leaflets.

Continued on page 4

### continued from page 3

After London, the My life, My gift mail drop campaign moved on to all 726,000 households in Northern Ireland in November. In the new year it will focus on major towns and cities in the north-west and north-east of England (January) and the Midlands (February).

The five regions have been targeted because they currently have the lowest sign-up rates to the ODR – ranging from 19% to 22%. It is anticipated the information will reach a total of 29.2 million people – 49.6% of the UK population.

Awareness of the maildrop is being boosted by local radio and cinema advertising, while UK Transplant is also keen to work with other commercial and public sector organisations during and beyond the



*Cinema ad coming to a screen near you.*

campaign to raise awareness of the need for more organ donors.

The campaign also seeks to encourage more people from black and Asian communities to join the ODR as they

are currently under-represented as potential donors - resulting in people from those ethnic backgrounds waiting up to twice as long as the white population for a transplant.

## Erin's new life enters the record books



**Toddler Erin Nicks became a transplant record setter just weeks before her third birthday after surgeons at the Birmingham Children's Hospital gave her a new liver and a new life.**

The two-year-old from County Armagh in Northern Ireland made history after receiving the 120,000th transplant to be registered on the National Transplant Database, 35 years after it was launched in 1972.

Erin underwent a first liver transplant at the hospital in June 2005 when she was just eight months old after doctors diagnosed her as suffering with biliary

atresia, a condition which causes bile to build up in the organ.

An infection caused her body to reject the liver two years later, but doctors say the new organ is functioning normally and she is doing well.

"We are overjoyed," said Erin's mum Orla, 32. "We were stricken with worry not knowing whether a new liver would be found. We had only just started to relax after the first transplant; we had even begun planning our first holiday."

Erin's dad Simon, 32, added: "Someone has given our daughter the most precious gift, the gift of life. It is such a selfless act and one which we will never forget."

The National Transplant Database is managed by UK Transplant and includes details of all donors and patients who are waiting for, or who have received a transplant, including some of those carried out in the UK before 1972.

In total it holds more than 200,000 entries, including 70,997 organ transplants, 49,003 ocular transplants, and 72,856 donors – both living and cadaveric – as well as the details of the thousands of people who currently need a transplant.

One of the first people to benefit from a transplant after the database was launched was Star Wars prop maker William Hargreaves, 53, from Bracknell in Berkshire.

The married grandfather of three had his kidney transplant when he was 17 and went on to work designing props for some of Hollywood's biggest blockbusters including *Return of the Jedi* and *Raiders of the Lost Ark*.

"It wasn't until a few years later when I started having a family of my own that I began thinking about the gift someone else had given me in their death," said William. "Without that gift I don't think I ever would have had my career, or more importantly my family."

## Life-saving mail drop goes to thousands of NI homes

Ice hockey stars the Belfast Giants helped launch the Northern Ireland stage of UK Transplant's My life My gift campaign with a special photo call at their training rink in the city.

More than 720,000 homes will receive a special leaflet inviting people to join the NHS Organ Donor Register (ODR) as part of the campaign in Northern Ireland. And the Giants are urging people in the Province to make the life-saving mail drop a big hit.

Currently more than 380,000 people have made their donation wishes known by joining the register, yet this equates to only 21% of the population in Northern Ireland making it one of the lowest sign-up rates in the country and below the UK national figure of 24%.

Also supporting the campaign is the family of Newry toddler Erin Nicks who was given a new future when she received a liver transplant in August (see p4 for full story).

"The My life My gift campaign gives the people of Northern Ireland the chance to send a message of hope and support to those desperately waiting for a transplant," said Todd Kelman, Belfast Giants general manager.



*Belfast Giants put their weight behind My Life My Gift campaign.*

## Promoting organ donation to BME communities

**UK Transplant has joined forces with two major organisations in a bid to encourage more people from black and minority ethnic communities to sign up as organ donors.**

The South Asian Health Foundation (SAHF) hosts regular meetings in local south Asian communities across the UK. These workshops are led by volunteer Asian medical professionals who wish to inform the Asian population about a wide range of relevant health matters.

Over the coming months SAHF will be promoting organ donation and transplantation as part of its community education programme. "We are delighted to be working with UK Transplant on this health promotion campaign," says Dr Rumeena Gujral, National Coordinator at SAHF. "Together we hope to trigger discussion at grassroots level about the importance of organ donation and transplantation."

UK Transplant is also currently working closely with the Policy Research Institute on Ageing and Ethnicity (PRIAE). Earlier this year PRIAE was awarded DoH funding to develop a health education campaign to encourage BME communities to consider donating blood, bone marrow, tissue and organs.

A series of consultation events is scheduled from November through to Spring 2008 to encourage people from the South Asian, African Caribbean and Chinese communities to think positively about being a donor. "Our *Being a Donor* project actively involves BME community members in considering the incentives and barriers to donation and then utilising this information to create an awareness-raising campaign that will engage their communities more effectively," said Yolande Watson, Project Leader at PRIAE.

Further information: [www.sahf.org.uk](http://www.sahf.org.uk) and [www.priae.org](http://www.priae.org)



# National Transplant Week message is poignant reminder of Robyn

**The theme for this year's National Transplant Week was 'What are you waiting for?' – a double-sided question showing that over 9,000 people in the UK are currently in need of a life saving/changing organ transplant, but that joining the NHS Organ Donor Register is something people can do now.**

The campaign poster featured Robyn Tainty, a cystic fibrosis patient who at the time had been waiting for two years for a double lung transplant. 4,000 posters were distributed throughout the UK to a variety of organisations including NHS trusts, schools, GP surgeries, companies, councils, libraries, media and individuals running their own organ donor awareness campaigns. Posters were also made available to Breath Easy Groups through UK Transplant.

The first launch of National Transplant Week was on 5 July at the House of Commons. It took the form of a reception with presentations from member organisations of Transplants in

Mind. Robyn made an emotional speech with the aid of oxygen, and help from fellow sufferer Emma Harris, about her life and what it is like to be on the transplant waiting list.

*Sadly Robyn died in September before receiving a transplant, but she bravely continued to raise awareness about the need for more organ donors right up until her death.*

Emily Thackray, had given a similar speech a year earlier whilst waiting for her lung transplant, but has since had the life saving operation. The contrast in health and vitality between Emily a year ago and now was amazing, showing the true gift of life a transplant can bring.

A second launch in Edinburgh on 6 July helped promote the Transplant Games being held there from 26-29 July. The launch in Edinburgh was as emotional, with speeches by Christine Evans (chairman TSUK) and transplant recipient Anna Burnett, taking part in the 2007 Edinburgh Games.



The launch was attended by MSP George Foulkes, who earlier in the week had tabled a motion in the Scottish Parliament in support of National Transplant Week and the Games. At the end of the launch a video on the World Games was shown, highlighting what can be achieved post transplant.

One of the aims of National Transplant Week is to increase awareness throughout the UK. The support of the media is therefore crucial and plenty of media coverage was given through the week. GMTV supported NTW again this year, and interviewed Robyn on the day of the launch. There was also coverage by ITV, BBC Scotland, on the BBC One Show, and local television. There was also coverage on national and local radio and by the press.

Some of the events held during National Transplant Week included:

- The Donor Family Gathering
- Month-long bus campaign by Travel West Midlands on 1,000 of their buses featuring the Robyn Tainty poster. Robyn was amazed that her face would be seen on the side of



***Determined to the end; Cystic fibrosis patient Robyn Tainty made her speech at the House of Commons launch. Sadly, Robyn aged 24 died two months later while waiting for her lung transplant.***

- buses all over Birmingham.
- The Precious Gift of Life Service
- Donor Bus in Cambridge (Addenbrooke's) and Bolton
- Three-week showing of the plays *Better* and *Afterwards* in London, written by transplant recipient Glenn Mortimer
- Midday Million-Mile Challenge with TSUK

The impact of the week was amazing. It is difficult to calculate how many additional registrations

were made to the NHS Organ Donor Register as a result of National Transplant Week. However early estimates are that at least 68,000 additional names were added as a result of the publicity and awareness campaign, local events, and through the Donor Bus. The dates for next year's National Transplant Week are 6-13 July 2008.

**Colin Day**  
Chief Executive - Transplants in Mind



**TIM Chairman John Wallwork and MSP George Foulkes at the National Transplant Week launch in Edinburgh.**

## UKT runners' marathon fundraiser

**UK Transplant staff helped raise awareness of organ donation, and more than £600 for charity, when they ran the Bristol half-marathon in September.**

The team of nine, from UKT's IT and communications departments, donned Organ Donor Register-themed vests for the 13-mile run. All members of the team completed the course, with times ranging from just under two hours, to just over two hours 30 minutes.

A total of £638 was raised in sponsorship for transplant charity Transplants in Mind (TIM), and the team's efforts were praised by TIM Chief Executive Colin Day.

He said: "Our thanks to the team for running the half-marathon and helping raise money for TIM. It's a great achievement and much appreciated by everyone here."

TIM also has places for runners in the British 10k race in London in July 2008. Anybody who would like to take part and help fundraise for TIM is invited to contact Colin on [colin@transplantsinmind.org.uk](mailto:colin@transplantsinmind.org.uk)



**(back row, l-r) Noel Davies, Clive Mangan, Sylvia Rodgers, Angie Burton, Nick Bryant, Cinzia Bryant (front row, l-r) John Oliver, Dominic Moody (Ninth runner James Gledson not shown.)**

## The Roy Pitman Society

**A new charity dedicated to promoting organ, blood and bone marrow donation will be launched in November.**

The Roy Pitman Society is named after an Army colonel and liver recipient, who ran the Addenbrooke's Hospital liver patients' support group for many years and was a staunch supporter of the NHS Organ Donor Register (ODR).

The charity will focus in particular on educating young people about the benefits of donation, as well as raising awareness of the ODR among people who may have signed donor cards prior to the launch of the register in 1994.

The charity will be officially launched by the Lord Mayor of Birmingham at the city's Copthorne Hotel on 9 November. Patrons include actor Ian Kelsey and Dr Graham Alexander.

Charity secretary Patricia Hall said: "We're very grateful to our patrons for their support and hope that by bringing together all types of donation the population will think very seriously about the subject.

"After all, one day any one of us may need a transplant and without the altruistic gift of life this would be impossible."

Contact Pat Hall 01772 321154

# UK team crowned champions at World Transplant Games



*Golden boys: l-r Peter Allinson, George Newman, Rahn Pullik, Matthew Barton.*

**The UK team has returned home triumphant after collecting a record haul of medals at the World Transplant Games.**

The team topped the tables in both the adult and children's medal tables in emphatic style, with the adult team winning more medals than both the second and third placed countries combined.

UK athletes arrived in Bangkok determined to defend their crown as 2005 champions in the face of stiff competition from sportsmen and women from 54 other countries.

And by the end of the week-long event the adult team had scooped 100 gold,

75 silver and 52 bronze medals, while the juniors won 30 gold, 19 silver and 17 bronze.

The adult team won medals in a variety of events, with St Austell kidney recipient Steve Jarvis winning four golds

in the 100m, the 4x100m relay, 4x400m and the high jump, where he set a new world record with a jump of 1.66m.

The team also created a splash in the swimming pool where students Matthew Dodd and George Newman both won five medals and the men's medley relay team, of which George was a part, also set a new world record.

In the junior section 13-year-old kidney recipient Adam Phillips was one of several successful competitors, bagging gold in the 100m, long jump and throw ball, silver in table tennis and bronze in the 4x100m relay.

Lynne Holt, UK team manager, said: "All the athletes at the World Transplant Games have to be at their peak of physical fitness to compete, making it a clear illustration of the value of organ donation.

"But perhaps more importantly, the Games put a global spotlight on organ donation.

"Bangkok was a fantastic backdrop to the event, helping to raise awareness among people from all races and religions.

"Returning to the Games as 2005 champions was without a doubt a challenge but every team member gave it their all and we are proud beyond belief to remain the overall winner.

"However, the true champions are those individuals that gave the gift of life, offering all these athletes their second chance to live."

The 2009 World Transplant Games will be held in Gold Coast, Australia, while the Winter World Transplant Games take place in Rovaniemi, Finland in March 2008.

## British Transplant Games 2008

**The 31st British Transplant Games will be held in Sheffield for the second time in its history with the majority of the activity being hosted by the University of Sheffield from the 7-10 August 2008. The Games are open to recipients of life saving organs from five to 70 years-old.**

During the weekend a donor run on Saturday 9 August is being planned. A 5k challenge and 3k fun run which is open to all members of the public, family and friends, and is an opportunity to raise some much needed funding for Transplant Sport UK. For details of the events or if you wish to volunteer your services over the weekend of the games please contact:  
office@transplantsport.org.uk or emma.dean@mls.gb.com or phone Mary Twomey, Administrator TSUK on 01962 865030.

## 50,000th Kidney transplant

**A little boy from Grimsby has a whole new future to look forward to after receiving the 50,000th kidney transplant recorded in the UK.**

Five-year-old Kyle Nuttall had spent most of his life in hospital before the landmark transplant at St James's Hospital in Leeds earlier this month. When he was just ten months old he was diagnosed with pneumococcal haemolytic uremic syndrome, an infection which led to chronic renal failure.

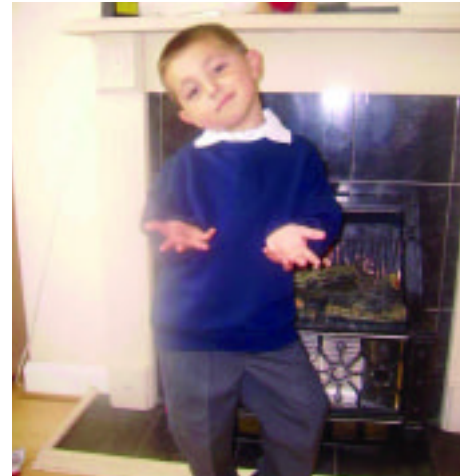
In the years that followed he struggled with his growth and weight, and was unable to enjoy everyday foods like bananas and potatoes or even occasional treats like chocolate because of the strict renal diet he had to follow.

Now Kyle is looking forward to being able to go back to school, play with his friends, and enjoy a chocolate treat for the first time in almost five years.

"He's a different boy," said Kyle's mum Jeanette, 24. "Before it was such a huge worry watching him having to go through dialysis and not being able to do all the things other children his age would take for granted.

"He's missed a lot of school, but now he can look forward to being with his friends again in the classroom and playground.

"He has a future and I'm so happy for him and so grateful to his donor too. Without their gift Kyle wouldn't have the second chance he's been given."



**Kyle's second chance.**

Kyle's surgeon, Mr Niaz Ahmad said: "The fact Kyle's kidney transplant is the 50,000th of its kind in this country is a wonderful and significant milestone. We should not forget though that the number of people needing a transplant far outweighs the number carried out. We are only limited in this respect by the number of organs available."

## 2008 London Triathlon

**The 2008 London Triathlon takes place in August and heart transplant recipient John Fisher is hoping to recruit a team of 40 to take part to raise money for his To Transplant and Beyond charity.**

The veteran marathon runner is assembling the fundraising team to further the charity's work to raise awareness of the importance of organ donation and to encourage more people to sign up to the NHS Organ Donor Register.

Twelve amateur athletes have already signed up including transplant recipients, co-ordinators and a surgeon. With team places still available John is encouraging more people to register their interest to take part.

"By putting the team together now we are giving people plenty of time to train to prepare for the race," said John, who has run 12 marathons since his heart transplant in 2000.



**John Fisher in action.**

There are three different races open to athletes of differing abilities, the longest of which, the Olympic distance race, involves a 1,500m swim, a 40km bike ride and a 10km run.

Contact John Fisher  
To Transplants and Beyond  
0845 6123 007  
[www.heart-transplants.co.uk](http://www.heart-transplants.co.uk)

## BMA survey

**The BMA produced a survey with YouGov in October revealing that public support is growing for a system of presumed consent for organ donation.**

The survey sampled over 2,000 people and showed that 64% of respondents said that the UK should move to a system of presumed consent.

The results of the survey also showed that only 26% of respondents said that their name was currently on the NHS Organ Donor Register but that 62% of respondents said they would be willing to donate their organs for transplantation after their death. The results also show that more women than men are currently signed up to the NHS Organ Donor Register.

# Transplant firsts offer new hope

**Surgeons have performed the UK's first paired kidney swap and adult to adult living liver donor transplants, heralding a new era in transplant surgery.**

The landmark operations were performed in the summer and offer new hope to those needing a transplant.

The paired kidney swap involved Cambridgeshire husband and wife Roma and Peter Horrell and a couple from Scotland, who do not wish to be named, while retired police officer Stephen Lomas was given a new lease of life by his liver donor son David.

Both kidney swap couples are doing well after their operations, which involved a donor and recipient couple whose blood or tissue type did not match being paired with a donor and recipient in the same situation.

Kidneys were exchanged by relay: one donor kidney was flown from

Edinburgh to Cambridgeshire and transplanted while the other couple's donor kidney was flown back to Scotland for a similar operation.

The operations were carried out by John Forsythe, consultant surgeon at the Royal Infirmary of Edinburgh, and Andrew Bradley, Professor of Surgery at Addenbrooke's Hospital in Cambridge. The new scheme was made possible by the introduction of the Human Tissue Act (2004) in September 2006. Before then organs from living people could only be donated to genetic relatives and to people with close personal relationships or emotional ties.

The scheme is regulated by the Human Tissue Authority, while UK Transplant is responsible for comparing tissue and blood types from couples on the programme to find potential matches. It is hoped the innovative scheme will lead to as many as 50 further life-changing transplants being performed every year.

**The adult to adult live liver donation also offers new hope.**

David Lomas, 20, from Cumbria donated part of his liver to his father Stephen, 51, who suffered with advanced liver disease. The successful, eight-hour operation involved two pairs of surgeons operating simultaneously in separate theatres at Leeds' St James's Hospital.

Dr Charlie Millson, a consultant hepatologist at the hospital, said: "The procedure involves removing part of the liver of the healthy donor and transplanting it into the patient with liver failure. The remaining liver in the donor will re-grow within weeks to almost its normal size.

"It is a tremendous breakthrough and really is a massive leap forward." Live adult to adult liver transplantation has been carried out in other countries for more than 15 years. This is the first time that this form of transplant has been performed in the UK. Other liver specialist centres commissioned to perform adult to adult liver transplants include Kings College Hospital in London and the Scottish Liver Transplant Unit in Edinburgh.

Chris Rudge, Managing and Transplant Director for UK Transplant, said: "Both of these transplant firsts are very welcomed developments - for the patients themselves and because it offers new opportunities for those still waiting for a transplant.

"The number of transplants involving living donors continues to increase each year, yet it is important to remember we would be far less dependent on these forms of transplant if it were not for the desperate shortage of deceased donors. It is still therefore vital that people talk about their donation wishes and join the NHS Organ Donor Register."



**Roma and Peter Horrell one half of the successful paired-couples kidney transplant.**

# Front row seats at a moment of history



**UK Transplant Principal Statistician Rachel Johnson and her colleague were on hand to view one half of the first paired living kidney transplant. Here, Rachel gives a personal insight into a momentous day.**

Jo Blackwell and I were very excited to be invited to watch the operations on one of the couples involved in the first paired donor transplant in the UK. We had spent many hours talking to surgeons, physicians, live donor co-ordinators and others to find out what sort of national scheme was needed, and a much longer time playing with our computers and looking at endless sets of data to develop the scheme. To be able to see for ourselves the benefits of this new form of living donation was an opportunity we were not going to miss.

When we arrived at Addenbrooke's early in the morning, Chris Watson came to meet us and told us that everything was in order and took us off to the operating theatre. We emerged from the changing rooms in our 'scrubs' (what a flattering look!) ready to watch

the donor nephrectomy. The theatre was busier than we expected – it was a very significant day, the operation was being filmed, and Jo and I were not the only spectators.

The other couple involved in this first kidney exchange were in Edinburgh and the first thing we saw was surgeon Andrew Bradley chatting on his mobile to John Forsythe – his counterpart in Scotland – to check that everything was ready at their end.

There seemed to be an air of nervous excitement as the operation started. It was to be a laparoscopic nephrectomy and soon various small incisions had been made in the donor and the tiny camera was in place.

What an amazing procedure – just how do they know where they are and which bits to cut? But even to us it was obvious that it was slow progress. Apparently the kidney was surrounded with some very obstinate fat and the tension seemed to mount as time passed. The team were clearly finding it a bit frustrating and in the end decided to convert to an open procedure.

In the meantime we heard that the Edinburgh team had performed their open nephrectomy and that the kidney was now in the air on its way to Cambridge. They were clearly going to have time for a break before they could start the recipient operation.

Not so in Cambridge, especially as the Edinburgh kidney, known to have two arteries but then found to have three veins, was going to take longer to transplant.

Things were starting to happen much more quickly in Cambridge. Apparently the donor had been warned that an open operation may be needed but would still be in for a bit of a shock

when he woke up with a much bigger scar than expected. It wasn't long before the kidney was removed and immediately perfused and cooled. However by this time the kidney from Edinburgh was already sitting in its box of ice in the corner of our operating theatre.

The Cambridge kidney was packed quickly into ice and sent on its way to Edinburgh. It had been a long morning and Jo and I took a welcome break whilst the donor left theatre and the recipient was prepared for surgery.

When we got back to the theatre Andrew Bradley had already started operating on the recipient.

There seemed to be an even scarier array of surgical implements to hand for this operation. And it seemed that even this part of the operation was not going to be straightforward – Chris Watson explained that one of the recipient's arteries was proving difficult to mobilise.

As the operation progressed Chris was working on the new kidney. Fortunately one of the veins was very small and could safely be tied off, but there were still two to deal with in addition to the two arteries. We watched in awe as Chris used a Y-shaped piece of artery that Andrew had removed from the recipient to make the two arteries into one (well, it wasn't really as simple as that, but that seemed to be the basic idea).

Chris hadn't used this technique very often and it was certainly very impressive. I hadn't realised how much patience these surgeons need! It was painstaking work and it must be difficult to concentrate and focus for so long. Every stitch was counted out and meticulously recorded before and after use – it was a real team effort.

Continued on page 12

## continued from page 11

Finally it was time for the kidney and its new owner to be united and Andrew began the next stage of the operation.

Although the kidney going to Edinburgh had taken such a long time to remove, it had only one artery and we heard that the recipient operation had gone smoothly. Whilst we were still in theatre it seemed that everyone in Edinburgh was now having a cup of tea and able to reflect on the day's events.

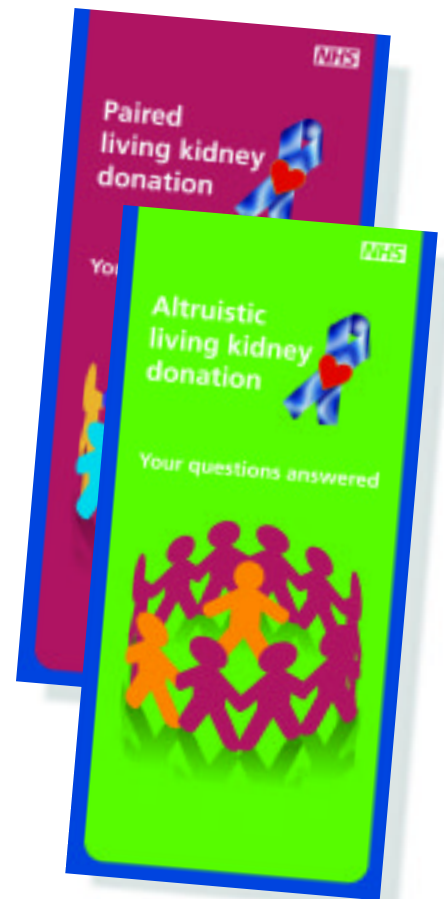
Jo and I were very concerned about hampering the theatre staff and getting in the way – they seemed to be constantly fetching, recording, monitoring and, we were pleased to note, filling in the UK Transplant data forms! But they kept smiling even if we were in their way and took the trouble to explain everything to us whenever they had the time.

Suddenly the calm was interrupted with a moment of alarm – something

was obviously not quite right but Jo and I didn't know what had happened. We kept well back in the corner of the theatre and exchanged anxious looks. It turned out that one of the arterial clamps had come off but Andrew very quickly sorted this out and the tension eased.

Andrew and Chris completed the operation together and we saw what we had all been waiting for – the new kidney turned pink and started to produce urine. What an amazing sight! It had been a long, tiring and at times a tense day, but this reminded us all why transplantation is so magical.

Having thanked everyone for their amazing hospitality, it was about 8pm by the time that we left Addenbrooke's to drive back to Bristol. We had both had the most incredible day and although all our work over the last year or more had made only a tiny contribution to the success of the day, it gave us immense satisfaction that we had been involved in some small way.



**Leaflets for transplant co-ordinators supporting the new altruistic and paired living kidney donation initiative.**

# Vinnie lends his support



**Former Premiership footballer turned Hollywood star Vinnie Jones is calling on more people to join the NHS Organ Donor Register, 20 years after his wife Tanya underwent a life-saving heart transplant.**

The star of *Lock, Stock and Two Smoking Barrels*; *Gone in 60 Seconds* and *X Men: The Last Stand* is patron of the charity To Transplants and Beyond and the latest celebrity to join UK Transplant's list of famous supporters.

The former Wimbledon footballer, who won the FA Cup with the club in 1988, said: "Ever since my wife Tanya had a heart transplant at Harefield Hospital

back in 1987, I've realised just how important organ donation is.

"I feel passionate about the whole issue of transplantation. Tanya became ill during her pregnancy with our daughter Kaley and but for the wonderful doctors at Harefield Hospital and, of course, the donor who made her transplant possible, I would have lost her.

"The very fact that we could renew our wedding vows 13 years after our wedding, watch our children grow and for them to have a mother and father is down to Tanya's transplant.

"It's vital that more people join the NHS Organ Donor Register."

# New Chief Executive for NHS Blood and Transplant

**Lynda Hamlyn has been appointed Chief Executive of NHS Blood and Transplant (NHSBT). She will take up the post early in the New Year.**

She joins the organisation from Westminster Primary Care Trust (PCT), where she has been Chief Executive since its inception in 2002, leading a PCT with a consistent record of high performance, delivering health services to a diverse population. In the most recent NHS annual survey, staff voted Westminster PCT as amongst the top 20% best organisations in which to work.

Lynda Hamlyn said: "I cannot think of a more worthwhile job than working to assure the supply of blood and blood components and increase the number of organ transplants - and lives saved - across the country. I am looking forward to working with colleagues across NHS Blood and Transplant to build on progress made to date and tackle together the undoubted challenges ahead."

The Chairman of NHSBT, Bill Fullagar, said: "Lynda's track record of leading and developing successful organisations, often through periods of considerable change, speaks for itself. I am delighted that she is joining us at such a crucial time for blood and transplant services."



Lynda joined the NHS in 1986 as Director of Services for North Hertfordshire Health Authority, following 10 years at the Greater London Council. In a career in the NHS spanning over 20 years, she was Chief Executive first of Northamptonshire and then Hertfordshire Health Authority, and a member of the National Specialist Commissioning Advisory Group. She is also a nonexecutive director of Stonham Housing Association.

She replaces Martin Gorham, who retired in July 2007. Barry Savery (Director of Finance) will continue as Interim Chief Executive until Lynda takes up her post.

## Heart transplant anniversary

**A medical milestone is celebrated on 3 December with the 40th anniversary of the world's first successful heart transplant.**

South African surgeon Dr Christiaan Barnard made headlines around the globe when he transplanted the heart of road accident victim Denise Darvall into 53-year-old patient Louis Washkansky.

His pioneering operation captured the public imagination and showed that even that most symbolic of organs, the heart, could be transplanted successfully from one person to another.

Heart transplants now save the lives of more than 160 people in the UK each year and since the service became available on the NHS in the 1970s, more than 5,200 patients have benefited from the generosity of a donor.

Thanks to the support of the transplant co-ordinators in providing case studies, UK Transplant will be marking the anniversary of Dr Barnard's groundbreaking operation with a national publicity campaign.



## Measure of success

Between 1 July and 30 September 2007, 2,371 requests were made by authorised staff to access the NHS Organ Donor Register:

- 32.1% of all cornea donors and
- 25.9% of solid organ donors were found to have registered their wishes on the register.

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.

# North Thames duo bring A&E focus to global audience

**North Thames donor transplant co-ordinators Paula Aubrey and Michele Tyler have been awarded the St John Ambulance Air Wing Travelling Fellowship. Here, they describe that the award will allow them to attend the global 2007 Organ Donation Congress and how the educational journey will benefit their work back in London.**

As regional donor transplant co-ordinators, our main role is to promote, foster and develop all aspects of organ and tissue donation. The critical shortage of donor organs for transplant demands that we explore all areas where the potential for organ donation exists.

As experienced co-ordinators, we have a particular interest in promoting organ donation with hospital accident and emergency (A&E) departments.

This is a comparatively new concept which desperately calls for much-needed attention from the transplant community worldwide in order to benefit transplant patients.

The North Thames Transplant Co-ordination team has identified that the A&E department does have a potential of organs for transplant. The team has proven that A&E is an area where donation rates can be increased (figure 1) and we believe that the encouraging results we have seen in North Thames can be replicated across the UK and, indeed, worldwide.

The November Congress – in Philadelphia, USA – will provide a platform for us to share and explore the challenges and perspective regarding the organ donor crisis, with particular

reference to the developing A&E programme.

Paula will be presenting a paper at the meeting on behalf of the North Thames team titled *Improving the supply of organs for transplant from the emergency departments in the UK: a retrospective audit of deaths and educational development strategies.*

The meeting will support an interchange of models of improvement relevant to solid organ donation and transplantation. It will also provide the opportunity to visit emergency departments in Philadelphia and spend time with fellow transplant co-ordinators from around the world in order to gain further insight into expanding the current donor pool from within A&E departments.

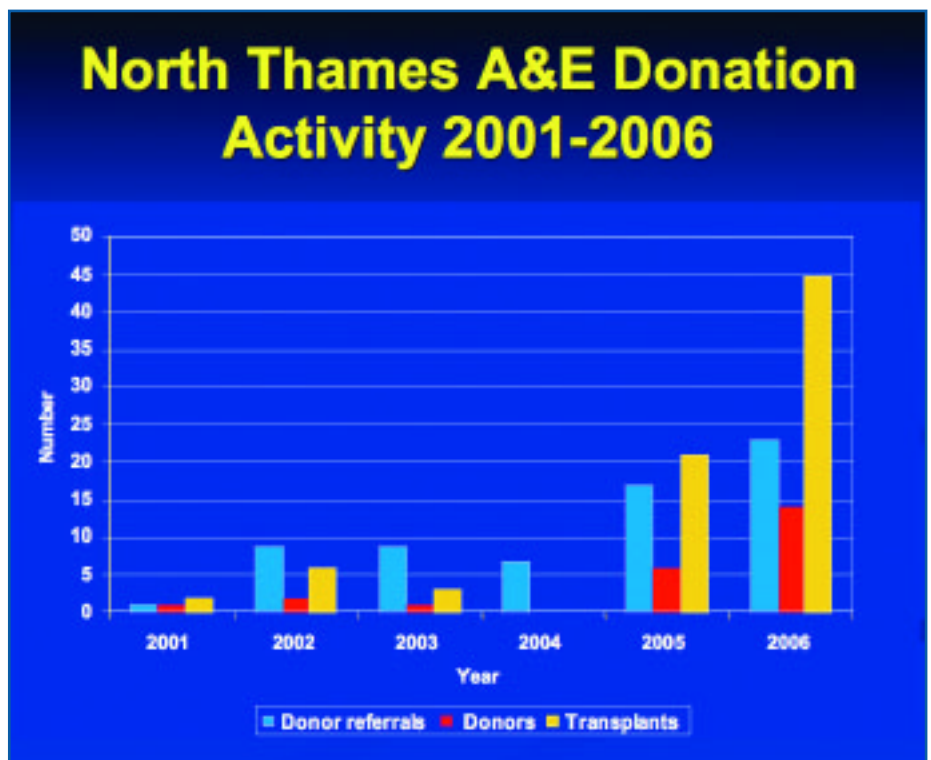
The four day conference will be followed by 1-2 days with the

Philadelphia procurement agency visiting emergency departments.

The overall purpose in attending the Congress is to gain a greater knowledge and to share ideas and experience that, in turn, will have an increased effect on the number of transplants performed by informing fellow transplant colleagues of best practice and health care policies.

We would like to thank St John Travelling Fellowship for supporting us in our work. We look forward to reporting back on our return.

\* In addition to the visit, Paula is studying for a PhD looking at organ donation from the A&E department. She is keen to speak to anyone wanting to share their views on the subject  
(Paula.aubrey@chelwest.nhs.uk).



# Record numbers of students sign up to save a life at UK Transplant superhero tour

**UK Transplant's tour of university freshers' fairs has enjoyed record-breaking success with the number of students signing up to be a superhero and save a life.**

The nation's universities are full of superheroes after thousands of them signed up during the tour of 14 campuses in September and October. An amazing 5,472 students signed up to join the NHS Organ Donor Register as the roadshow toured freshers' fairs. The figure was a 34% increase on the number who signed up last year.

The tour started with a flourish at Leeds University where 510 students signed up, the highest number of signatories at a single event in the five years that UK Transplant has been running its tours. Although no other event matched the success of the Leeds fair, events at several universities beat their own records for the number of sign ups.

Jennifer Pulcher, a student who signed up at the Manchester Metropolitan University freshers' fair, said: "It's a good idea to donate because it may save the life of others when mine's already gone. Why take my organs to



**Leeds students I-r Josh Holland, Annie Gamble and Bertie Farrow holding promotional fluffy bugs.**

the grave when others may need them?"

This year's stand developed last year's superhero theme, with the addition of a female companion to the original male superhero. Giveaways, including specially designed badges and temporary tattoos proved very popular amongst students, and provided a talking point on campus long after the event. A life-size superhero cut-out at the stand provided an extra attraction, allowing visitors to transform from their mild-mannered student persona into a caped crusader ready to save lives.

"The support from students this year was better than ever and we were delighted with the fantastic number

who took the positive step of joining the register," said Kate Baldwin, UK Transplant's campaigns and marketing officer. "One of our particular aims was to encourage students from ethnic minorities to consider organ donation. It is too early to say whether the statistics back this up, but black and south Asian students made up a significant proportion of visitors at many of the fairs which was really encouraging."



## Music fans join register at Bestival Festival

Nearly 100 music fans showed their support for organ donation at the Bestival music festival on the Isle of Wight in September by joining the NHS Organ Donor Register.

The UK Transplant team took the organ donation message to the heart of the summer's most colourful festival after being invited along by its organiser, Radio 1 DJ Rob da Bank.

Sue Pioli and Elinor Curnow were the lucky UKT employees who got to don their ruck sacks and pitch their tents for the three-day music marathon. They handed out more than 1,000 organ donor badges and tattoo-stickers from the good causes tent where nearly 100 music lovers joined the NHS Organ Donor Register.

"The response from festival-goers was really positive" said Sue. "It was a busy few days, but well worth the effort as so many people wanted to know more about the register and how they could help."

Rob da Bank, who is one of UKT's celebrity supporters, said: "From a young age I knew how important transplants were and the hope they offer to thousands of people of living a normal life, which is why I'm registered on the Organ Donor Register."

"Now, more than ever, I feel it's essential that people who need a transplant have the chance of staying alive – so please support the cause, talk to your family and friends about your wishes and, like me, join the Organ Donor Register."

This isn't the first time UKT has visited a summer music festival raising awareness of organ donation and the ODR.



**Top: Super heroes Sue Pioli and Elinor Curnow from UKT. Above: Sue and Elinor talk to a festival goer.**

In 2003 it attended the world famous Glastonbury Festival where more than 300 people signed up to the register. Angie Burton, UKT Marketing and Campaigns Manager, said: "Festivals are a great way of reaching a large footfall of people in one place. It's fantastic to see that so many kind-hearted people joined the register at Bestival and we are now looking at attending more festivals in 2008."

## On-line game re-launched

**UK Transplant has re-launched ORGAN-ise, the popular on-line game which invites people to be lifesavers by playing the game and joining the NHS Organ Donor Register.**

ORGAN-ise challenges players to test their medical skills in a bid to perform as many transplants as possible before the time – and organs – run out. Each week the best virtual surgeon gets to

win their own copy of the classic *Operation* boardgame. People are encouraged to play the game then forward it to friends and spread the word about organ donation.

"It's a bit of fun, but behind the game is the more serious message about the chronic shortage of organs," explained UKT's Campaigns and Marketing Officer, Kate Baldwin. "Players are reminded of the need for

more people to consider pledging the gift of life and sign up to the register."

Inspired by the classic *Operation* boardgame, ORGAN-ise was first launched in 2005 to complement the tour of university freshers' fairs. It quickly gained popularity in its own right reaching the top slots in many viral games charts. After an update, the game is now back on-line. To play the game visit [www.organ-ise.org.uk](http://www.organ-ise.org.uk)

# Monitoring transplant outcomes using CUSUM methodology

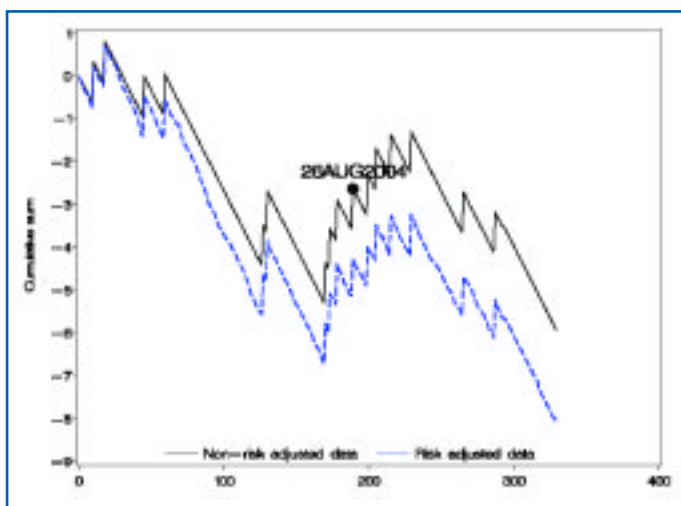
**Monitoring the success - or otherwise - of transplants provides valuable information. Sue Pioli, a senior statistician at UK Transplant, looks at one method for doing this.**

Patient and graft survival in each renal, liver and cardiothoracic transplant centre is routinely monitored to detect any changes in short-term outcome.

The monitoring process is based on Cumulative sum (CUSUM) charts, which compare short-term centre-specific mortality rates with expected mortality rates based on recent past performance. CUSUM monitoring has been carried out by UKT for a number of years, but now CUSUM charts are sent to individual centres to assist with internal audit. The aim of this article is to provide some explanation of how these CUSUM charts are interpreted.

In an Observed-Expected (O-E) CUSUM chart, illustrated in Figure 1, the difference between the observed and the expected mortality rate is plotted against the transplant number. For this purpose, the expected mortality rate is generally taken to be the proportion of transplant failures in a period of time immediately prior to the start of the monitoring period.

Transplants are monitored in chronological order and each successive transplant contributes to the CUSUM. If the outcome is a success, the observed mortality rate is zero, and the chart goes down a small step, reflecting the expected mortality rate or probability of death. If the outcome is a death, the observed mortality rate is one, and the chart goes up by a larger step reflecting the expected success rate or probability of success.



**Figure 1: An example of a O-E CUSUM chart.**

The cumulative sum charts will, over time, display a downward trend where the current mortality rate is lower than the baseline period, and an upward trend where the observed mortality rate is higher than expected. (See figure 1).

Risk-adjustment is used to account for changes in patient case mix compared with those transplanted in the baseline period. Risk-adjustment calculates an expected mortality based on number of factors, (such as recipient age, donor age, donor type etc) which contribute to a patient's chance of survival.

In the risk-adjusted CUSUM, high risk patients will have a greater expected mortality rate than the low risk patients, according to their risk scores. So, if a centre is transplanting higher risk patients than those transplanted in the baseline period, the risk-adjusted CUSUM displayed will be lower than the non risk-adjusted CUSUM, as in Figure 1.

If, however, the patients transplanted in the monitoring period are not as high risk as those in the baseline period, the risk-adjusted CUSUM will be higher than the non risk-adjusted case.

It is difficult to determine from the O-E chart whether a significant change in performance has occurred. A tabular CUSUM chart is used to complement the O-E chart and is designed to 'signal' or 'trigger' when mortality rates exceed a pre-determined rate, usually one and half times or twice the expected rate.

When a signal occurs on the tabular CUSUM it is superimposed on the O-E chart with the transplant date. The chart displayed in Figure 1, signalled for a transplant performed on 26 August 2006.

A signal is an indication that there has been a significant increase in the current mortality rate. This may be the result of a short run of unrelated poor outcomes, a change in patient case-mix or deterioration in centre performance.

In the event of a signal initially there is a careful review of the data to ensure it is accurate. The chair of the appropriate UKT Advisory Group is then informed and the centre is requested to review the patient deaths leading up to the signal and report.

CUSUM monitoring has been carried out in this way for liver and cardiothoracic transplantation since November 2006. Recently CUSUM charts for kidney transplantation have also been sent out to centres to help with internal audit. A similar CUSUM monitoring process for pancreas transplantation is currently being developed for introduction in the new year.

# ...Dr Martin Smith

Dr Martin Smith is a consultant in neuroanaesthesia and neurointensive care and the director of the neurosurgical critical care unit at the National Hospital for Neurology and Neurosurgery, University College London Hospitals. He has been a consultant since 1990 and his particular clinical interests are in neurotrauma and vascular brain injury. Dr Smith has been a powerful advocate for organ donation for many years and currently chairs the UK Transplant Donation Advisory Group and is a member of the Ministerial Task Force on organ donation.



On top of all this, Dr Smith leads an active multidisciplinary research group with an interest in optical methods for monitoring the injured brain. He is on the editorial board of the *Journal of Neurosurgical Anesthesiology*, a member of the Board of Directors of the Society of Neurosurgical Anesthesiology and Critical Care and has recently completed a term of office as President of the Neuroanaesthesia Society of Great Britain and Ireland. He has co-authored several national guidelines on neuroanaesthesia and neurointensive care and published widely on organ donation issues.

**Q What prompted you to specialise as an intensivist?**

**A** I was drawn to intensive care medicine because I enjoy the rapidly changing environment where the effects of interventions are seen in relatively short timescales. I work in a specialised area of intensive care medicine – neurointensive care. Some of the most challenging areas of medicine include traumatic and vascular brain injury and many of our patients are young – compared to a general intensive care population. Neurointensive care offers real benefits for these patients in terms of reduced mortality and improved neurological outcome. It is a challenge but also a great privilege to care for patients at such a critical period in their lives. Many of them are restored to their previous health after an illness that brought them close to death or facing the prospect of severe long term disability. Neurointensive care is rapidly evolving and expanding and we are only just beginning to understand the benefits that it can bring. It is an

exciting time to be involved in this area of medicine.

**Q What else might you have done?**

**A** As a medical student I believed that I would become a surgeon but I saw the light during my 'house jobs'. As my background training is in anaesthesia I suppose I might have become a full time anaesthetist. However, from a very early point in my postgraduate training I intended to become an intensivist. I was privileged to work with several first generation intensive care physicians in London during my training and their knowledge, skills and dedication were an inspiration to me and many others at that time.

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

**A** There are two that stand out. It is difficult to underestimate the satisfaction of seeing a patient, restored to full health, return to the ICU some months after discharge. This is particularly so if they had undergone a

stormy course on the ICU as a result of their severe head injury for example.

The second is the enormous sense of satisfaction I get working within a truly multi-disciplinary team. Besides working closely with senior medical colleagues from neurosurgery, neuroradiology and neurology, I spend most of my working life alongside some of the best nurses, therapists and other professionals that it could be possible to meet. The success of neurointensive care depends entirely on the whole team and this is one of the great lessons that trainee doctors learn when attached to my unit.

**Q What aspect do you least enjoy?**

**A** Juggling beds on an almost daily basis. I work in a city where neurointensive care beds are a scarce resource and maintaining access for emergency patients can be a real challenge. Many of these referrals require definitive treatment within a very short timescale to maximise their chance of a good outcome. For example, an expanding intracranial haematoma should ideally be evacuated within 4 hours of injury. It is my opinion that the primary role of a neurointensive care unit is to ensure timely access for such patients but this can of course put pressure on other areas such as the elective neurosurgical cases.

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

**A** Again, there are two completely different successes that I would like to

mention – one personal and the other related to the ICU team. On a personal level, I have recently completed a two year term of office as President of the Neuroanaesthesia Society of Great Britain and Ireland. It was a great privilege to be elected to that post by my colleagues and peers and to serve the Society.

On a professional level, the ICU that I lead has developed, like many others, a protocolised approach to the management of many neurological disorders. Our protocols have been used as the basis for local protocols by some other units in the UK but have also been exported to at least 8 other countries. This reflects a huge success for our multi-disciplinary team as well as being great PR for our unit!

**Q What one piece of advice would you give to someone new to intensive care?**

**A** Keep patients' relatives and friends well informed at all times and gain their trust. Unfortunately not all patients do well and, under these circumstances, it

is important for relatives/friends to be aware of the possibility of a poor outcome and also to be confident that their loved one has had the best possible chance of recovery.

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

**A** Two points. The first has been the reduction in the potential pool of brain stem dead heartbeating donors. In my opinion we have not seen the end of this trend as new treatment options, such as decompressive craniectomy, become more widely applied. It is therefore important that other donation options, such as non-heartbeating donation, become more widely available so that we can fulfil the wishes of patients who wish to donate their organs after death.

The increasing involvement of donor transplant co-ordinators with potential donor families at an early stage is a massive improvement for donor identification and management. I am

very positive about the concept of 'in-house' donor co-ordinators and very much hope that this scheme, or something similar, can be extended.

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

**A** I suppose that at this stage in history I would have to say sort out MMC and MTAS. I am not against the fundamental concepts of MMC but history will not view its implementation via MTAS positively. These problems have implications far beyond individual doctors and extend to the wider NHS.

If MTAS had not been topical my focus would be on ensuring equity of access to all services by all patients. Despite the rhetoric, there are still too many examples of 'postcode' delivery of care and of the inability of some sections of the population to access care.

**Q How do you relax?**

Travelling, listening to music and enjoying fine wine.

## ADVISORY GROUPS

### Pancreas Task Force

*PTF met on 27 April 2007*

- NCG have agreed to fund the cost of improving the speed of transfer of organs between centres with particular reference to the scheme for managing sensitised patients.
- A pancreas donor form to be completed at retrieval is currently being developed as well as a separate form to accompany the organ to the transplanting centre.
- A proposal to develop the Pancreas Task Force into a UKT Advisory Group in its own right to reflect the increasing numbers and the importance of pancreas transplant programmes in the UK was endorsed. The chairmen of the Kidney and the Pancreas Advisory Groups will attend the reciprocal advisory group.
- NCG formally confirmed its intention to suspend indefinitely the pancreas transplant programme at the Royal Liverpool University Hospital and will not consider any further bids from centres for entry onto the programme until 2010. Pancreas retrieval zones were therefore realigned in light of this change and centres can retain organs retrieved within their new zones.

- A proposal has been developed to implement a national pancreas allocation scheme for sensitised patients. An application is in place to enable UKT to calculate the reaction frequency for each patient, with a second phase to implement an application to allow the UKT Duty Office to offer donated pancreata, in the first instance, to individual compatible sensitised patients on the active pancreas transplant list. Individual compatible sensitised patients listed nationally will be offered pancreata before offers are made to individual centres. Pancreas waiting time will start from the date of active pancreas registration and end if the patient is transplanted or removed from the list. The issue of offering priorities between kidney-only and kidney/pancreas patients was referred to the next meeting of the Kidney & Pancreas Advisory Group. Dual registration arrangements will no longer exist once this scheme is implemented. UKT will circulate a monthly report of all patients listed showing their scores and those who have an HLA reaction frequency of 30% or higher to enable clinicians to advise patients who are sensitised that they should go onto the kidney-only list or kidney/pancreas list.

- A proposal to amalgamate the pancreas transplant waiting lists for Edinburgh and Newcastle was endorsed with the intention that it should commence as soon as possible, subject to recalculating a new balance of exchange, removing any exchanges between these two centres since the national sharing scheme had commenced. This proposal will relieve the pressure on both centres when a local donor becomes available and results in a liver and a pancreas (or kidney and pancreas) transplant taking place on the same day, putting pressure on surgical, anaesthetic and theatre staff.
- When a patient moves from a kidney-only list to a kidney/pancreas list the date of activation should be counted as whichever is the earliest activation on either list.
- Data on the results of pancreas transplants within the UK was recognised as an important issue for patient choice and centres should be monitoring their activity. Due to the limited numbers involved this data should only be available in the public domain with appropriate summaries detailing confidence intervals, timescales and additional information on the reliability of the data. The starting point for reporting of data should be from the time of commencement of NCG funding with a time period to be agreed by UKT Statistics & Audit Directorate.
- Pancreata from donors up to the age of 55 are offered nationally. In addition, Cardiff, Manchester, Edinburgh and Oxford are happy to receive offers of pancreata from donors aged up to 60 years. Following a preliminary analysis of the effect of donor age on pancreas transplant outcome it was proposed that the lower donor age limit of eight years for kidney/pancreas donation is removed, subject to endorsement at the next KPAG meeting.
- When developing new allocation arrangements members agreed to consider schemes that minimise cold ischaemia times, irrespective of whether pancreata are used locally or are imported.
- The next meeting of the UK Pancreas Forum will be held in Cambridge on Friday, 1st February 2008.
- The new elective liver recipient registration form was endorsed by LAG.
- The offering sequence for a donor liver that meets the previously agreed criteria for liver splitting was discussed and minor amendments agreed. The "index patient" is defined as the patient who, in accordance with the national offering sequence, will receive the whole liver or a reduced portion of that liver if, for technical or other reasons, the liver is not splittable. The transplant centre caring for the index patient is responsible for arranging the split procedure. If that centre lacks a surgeon capable of performing the split then a surgeon from the centre accepting the other portion of the split liver will need to attend to perform the split.
- Livers from the ROI are to be fast-tracked and UKT representatives will discuss with the Irish Department of Health & Children concerns over donor transplant co-ordinators putting restrictions on time limits which are likely to cause difficulty in UK centres arriving in time to retrieve organs.
- Members agreed there should be no change to the policy whereby if a patient is suspended from the super-urgent transplant list, when they are reactivated they move to the bottom of the list.
- A proposal for paediatric patients with hepatoblastoma to be listed as a national priority after super-urgent patients and liver/bowel patients was endorsed. This would apply to all children who are judged as transplantable by current hepatoblastoma criteria. The proposal states "At the time of evaluation for hepatoblastoma, if it is deemed unresectable then a window of 4 weeks should be identified when the child is listed as super-urgent. During this time the child would be considered as taking less priority than super-urgent listings and, where possible, identical blood groups should be accepted. Children under two years of age could be considered for cross blood group transplantation." UKT to advise the liver recipient co-ordinators of the new policy.
- Proposed guidelines for liver transplant assessment in the context of illicit drug use were tabled and endorsed, although not unanimously. Work is to take place in conjunction with representatives from Edinburgh on collating further data on which to focus a more detailed study.
- A research grant has been obtained to help widen clinical use and cover development costs for a national organ retrieval imaging system within UK liver centres. In addition, UKT will host the website and negotiate on funding of the software. Ideally every retrieval team will be supplied with a camera and transplant surgeons will have access to a PDA to view images when considering offers. LAG endorsed continuation of these negotiations.
- Patients with alcoholic hepatitis are not currently considered as candidates for liver transplantation. A study was carried out into the use of orthotopic liver transplantation in a small cohort of patients with alcoholic hepatitis to determine whether good outcomes can be obtained in selected patients. LAG felt that this work should not be supported at this time but agreed with the need to establish a process to define the guidelines on how innovations in transplantation are judged going forward.

### Liver Advisory Group

#### *LAG met on 23 May 2007*

- The pilot study between Edinburgh and King's for auxiliary partial liver transplantation for highly sensitised kidney transplant candidates at the time of kidney transplantation was approved in the context of domino transplantation.
- The proposed selection criteria for patients onto a transplant list for adult orthotopic liver transplantation were endorsed subject to future amendments to the criteria for hepatocellular carcinoma (HCC). The current criteria for HCC will remain until this issue has been resolved.
- The proposed policy for the allocation of donor livers and the national distribution of organs for adult liver transplantation from deceased donors was endorsed. Further consultation will take place on selection and allocation policies for children.

- Potential multi-visceral transplant recipients should receive priority for adult organs. This has not transpired partly due to a failure to get consent for such transplants and significantly due to the issue of access to smaller donors. Agreement was reached on a modification to the organ allocation policy to allow access for multi-visceral recipients to appropriately sized paediatric donors, based on weight, as is the case in the USA and the rest of Europe on the basis that in the case of any conflict a paediatric recipient should take priority over a multi-visceral recipient. *(Post meeting note: further clarification is currently being sought on the offering sequence in relation to paediatric and adult multi-visceral recipients.)*

### Kidney and Pancreas Advisory Group

**KPAG met on 8 June 2007**

- The British Association of Paediatric Nephrologists (BAPN) has agreed to incorporate a general statement relating to intelligent mismatching in the guidance for the transplantation of paediatric recipients.
- A mechanism to redress the disadvantage through the kidney allocation scheme in cases of transcription error will be established by the end of August 2007.
- St James's University Hospital, Leeds had previously requested that the maximum donor age for kidneys offered to paediatric units be raised to 55 years. However, this was not supported at a subsequent meeting of the BAPN. Further work is taking place at UKT on the benefits of age versus matching for paediatric recipients.
- A pilot in the North Thames area to allow blood group B patients to receive blood group A2 donor kidneys has resulted in 21 blood group 'A' donor kidneys being tested, four of which were A2. Of these, one kidney was successfully transplanted.
- The following proposals to improve the use of extensive national data sets relating to UK kidney and kidney/pancreas transplant activity and outcome data were endorsed:
  - Establishment of a research advisory group reporting to KPAG twice pa, to replace the existing audit & analysis sub-group
  - Strengthening of governance arrangements for collaborative projects with transplant centres
  - Strengthening of governance arrangements for individuals who undertake analyses themselves
  - Prior agreement between UKT and the collaborating transplant centre/ individual on arrangements for the presentation and publication of research findings.
  - An oversight group to discuss clinical issues arising from the paired donation scheme, and which could also consider issues relating to altruistic non-directed donation, is to be established.
  - Results from the first twelve months of the 2006 National Kidney Allocation Scheme (NKAS) mirrored those at six and nine months. The previously agreed phasing-in process was removed as from April 2007 and an improved method of identifying centres requiring additional points was introduced.
- Following the introduction of the 2006 NKAS there was no formal agreement on which centre has the choice of kidney when these are allocated. Currently the centre whose patient is highest on the national kidney matching run has the choice of which kidney they would like to accept. For some children the anatomical details of the kidney can be significant, therefore if there is a paediatric recipient in the top two on the matching run or a kidney/pancreas recipient then the order of priority was agreed as:
  1. Paediatric kidney-only patient
  2. Kidney-pancreas patient
  3. Adult kidney-only patient
  - Due to the small numbers involved it was agreed to allow the retention of all accrued waiting time for those patients whose grafts fail up to 180 days who are re-listed for transplant. This would also apply to transplants from a living donor.
  - There is currently insufficient data on which to base a decision on establishing a national allocation scheme for non heartbeating donor kidneys. It was agreed that local centres can share these organs in order to limit cold ischaemia times. Any centres wishing to enter into a local agreement should inform the Duty Office at UK Transplant before doing so.
  - An audit of non heartbeating donor referrals between 1 April 2006 and 31 March 2007 demonstrated that there is significant room for improvement both in the initial identification of non heartbeating donors as multi-organ donors and in the offering nationally of all organs. Appropriate arrangements must be in place locally for the facilitation of non heartbeating donors as multi-organ donors.
  - KPAG members supported the proposal for separate advisory groups for Kidney and Pancreas.
  - KPAG endorsed the introduction of a new sensitised patient scheme for pancreas allocation. As a result patients can only be registered at one centre for either a kidney-alone or a kidney/pancreas transplant. A decision on offering priorities between kidney-alone and kidney/pancreas patients was deferred to allow the new scheme to be introduced and monitored for its effect before any additional priority is agreed.
  - In response to a request from the Pancreas Task Force to remove the lower donor age limit of eight years for kidney/pancreas donation KPAG requested an investigation into the effect of this proposal prior to making a decision.
  - KPAG considered pancreas and kidney retrieval from non heartbeating donors for combined transplantation. There is no obligation for a centre to give up a kidney in this situation but if centres want to come to a local agreement they may do so.
  - KPAG endorsed a decision from a recent meeting of the European Organ Exchange Organisations that if a patient is on the kidney transplant list in one country and moves their residence to a different country, the appropriate waiting time allowance in kidney allocation will transfer with the patient. The waiting time allocation will be that defined in the new country's allocation system.

### Ocular Tissue Advisory Group OTAG met on 20 June 2007

- It was acknowledged that a flu pandemic would impact upon eye donation and that one of the eye banks should remain open to deal with emergencies, subject to the constraints of a pandemic.
  - Donors who have a history of blood transfusion will not automatically be excluded from donating ocular tissue. This decision will be reviewed in 2008.
  - The OTAG audit and analysis sub-group reviewed how projects are to be formulated and approved in the future and the mechanisms involved. It is anticipated that the process for a project to be approved should take no longer than three months. Comments on the transplant record and follow-up forms should first be submitted to the OTAG audit & analysis sub-group for prioritisation and, if necessary, amendment prior to submission to OTAG for endorsement or otherwise. It is necessary for prioritisation to take place due to the current restrictions on IT resources.
  - Data on the use of antiviral prophylaxis following corneal grafts showed that the long-term use of post-operative antivirals indicates improved graft survival. Due to limitations in the data available, however, it is not possible to determine the exact length of time on antivirals.
  - The Human Tissue (Quality and Safety for Human Application) Regulations 2007 brought the EU Tissue and Cell Directive (EUTCD) into law on 5 July 2007. The regulations make it an offence to import and export human tissues and cells for human application without a licence from the Human Tissue Authority (HTA) or a third party agreement with a licensed establishment. All relevant individuals need to be aware of the implications of not complying with these regulations.
  - There is a lack of clarity regarding the fact that direct authorisation provision within the Human Tissue Regulations 2007 relates only to bone marrow and not to limbal allografts. This has become a critical issue for transplant surgeons wishing to carry out the local retrieval and use of ocular tissue for a limbal transplant within 48 hours in a transplant centre that does not hold a licence. There was concern that the requirement for this licence will impact on the number of centres prepared to undertake limbal transplants. The options available to centres for them to continue to undertake limbal transplants are:
    - Apply for a licence for procurement, processing, testing, distribution, and import and export.
    - Enter into a third party agreement with a centre that already holds this licence.
    - Develop specialist centres licensed to carry out this procedure.
- Entry into a third party agreement would be a practical option. The possibility of the licensed eye banks acting as the designated individual for some centres would also be considered.
- The HTA Code of Practice on the import and export of human bodies, body parts and tissue clarifies that authorisation in Scotland is equivalent to

consent in the rest of the UK and that if tissue is to be used for therapeutic purposes then movement across the Scottish border is not deemed to be import/export. It will still be classed as import/export if the tissue is to be used for research. Discussions are ongoing on a suggestion that if the tissue for research is from a UK donor then this should not be classed as import/export.

- Currently an informal policy exists on the cancellation of corneal requests when there is insufficient material. On these occasions the UKT Duty Office has to contact some centres one week prior to the scheduled graft date to advise that the graft needs to be rescheduled. Centres are contacted on a 'first come, first served basis'. If the consultant considers the graft to be essential then the request will be honoured and an alternative graft cancelled. OTAG agreed that this practice should continue. If a patient is non-HLA matched and has their transplant cancelled the patient should be given a higher priority than other routine non-HLA matched requests. Therefore, if the patient's transplant is cancelled because there is not enough tissue available then that patient can have a rescheduled date agreed with an extension to the three-month window permitted for the ordering of ocular tissue.
- The allocation priority for corneal tissue is:
  1. Emergency requests (perforation or threatened perforation)
  2. Requests for paediatric patients (aged less than 8 years via the paediatric allocation scheme)
  3. Requests for matched material for HLA tissue typed donors
  4. Routine non-HLA matched requests
- Guidance from the Department of Health on the 18-week measurement of referral to treatment is that the clock stops on the date the decision to add a patient to a transplant list is communicated to the patient and their GP. This rule applies to both organ transplants and corneal transplants.
- The maximum age threshold for recipients on the paediatric corneal allocation scheme was agreed as less than eight years old and material from donors less than three years of age would not be considered for corneal grafts although material from this age group may be considered for stem cell grafts.
- It was reiterated that to minimise the risk of corneas being issued and not used centres should contact the patient four days before the scheduled transplant.
- The Corneal Transplant Service (CTS) eye banks have provided a formal training programme for personnel who have more recently started to undertake eye retrieval but there is, as yet, no formal assessment of competency for non-NHSBT eye retrieval personnel. It was proposed that the eye retrieval scheme be linked to the potential competency framework designed for NBS staff working in tissue donation, although this would not resolve the issue of those staff who fall outside of either NBS teams or eye retrieval schemes. Prior to the proposed framework being rolled out the eye retrieval modules need to be reviewed against the training previously delivered by the CTS eye banks against the College Training and NHS Modernising Medical Careers programme. In addition NBS Tissue Services and the eye banks need to identify and list sources of information for those parts of the module not covered by the curricula. This would then enable formulation of an eye retrieval module for junior doctors,

which could be taken forward to the Royal College of Ophthalmologists.

- Body mapping should be carried out only on accessible body surfaces, marking on the body map those areas that have been examined.
- Donor age criteria for sclera were amended by the Ocular Tissue Transplant Standards Group (OTTSG) and endorsed by OTAG. Currently donors have to be less than 60 years old. This was changed to consideration on a case-by-case basis, based on inspection in the eye bank looking for calcification. In the case of corneas, OTTSG agreed to await further analysis of data before deciding whether to increase the age gap to 30 years.
- It is the responsibility of the person who takes the consent and carries out the donor assessment (organ and tissue co-ordinators) to pass to UKT, and therefore the eye bank, any additional information gained during retrieval of the eyes. Any supplementary information gained by the eye retriever should then be reported via the donor information form and the co-ordinator to UKT.

### Donation Advisory Group

*DAG met on 23 July 2007*

- The Human Tissue Authority has confirmed that the removal of blood for essential analysis, without consent, after confirmation of death by brain stem testing is lawful in support of the donation process.
- The issue of coroner refusal has now been transferred to the Ministry of Justice for consideration.
- It should be the decision of the individual clinician as to whether to exclude an organ donor who had previously received a blood transfusion. However, there are currently 23 people who are known to have received a blood transfusion from a blood donor who has subsequently developed vCJD. These patients should be excluded from all donations.
- The publication of the Organ Donation Task Force report and recommendations has been put back until early October 2007.
- A report on lessons from the Potential Donor Audit relating to comprehensive donor identification illustrates the need for an early and collaborative approach and a resolution of conflict with the police and coronial process. This information, together with a commentary on the data, will be submitted to the Task Force.
- A background paper on the relevance of using a trigger point referral protocol for potential donors was considered and DAG discussed the merits of having a mandatory trigger for notification. The recommendations under consideration contained no explicit 'clinical trigger' for notification to the donor transplant co-ordinator as it was felt that the key to success in taking the recommendations forward is the unequivocal support of clinicians working in critical care. Although some members expressed concern that the recommendations did not go further, DAG accepted the need to move forward with the support of the intensive care community and all members endorsed the recommendations subject to minor changes to the wording. Those units that do have existing clinical triggers should not be discouraged from continuing to use them. These recommendations will be submitted to the Organ Donation Task Force.
- The recent liaison between the ICS and the Organ Donation Task Force was recognised as highly significant in improving links between the two communities and members encouraged the establishment of more formal links. It was suggested that the transplant community should have a greater presence at ICS events, in particular the targeting of these events for submission of abstracts.
- A final version of the revised PDA form was approved by DAG. It is anticipated that the form will be produced as a web-based application that can be accessed on line, the details of which are still being developed.
- The Assessment of Collaborative Requesting (ACRE) trial was established to determine whether collaborative requesting to the families of brain-stem dead patients increases the consent rate for donation compared with requesting solely by the local clinical team. Where in-house co-ordinators are employed and collaborative requesting is occurring on over 50% of occasions, units will be excluded from the ACRE study. However, if collaborative requesting is occurring on less than 50% of occasions, units will be entitled to join the study.
- A working group was established to formulate guidelines on the management of paediatric organ donors. It is hoped to either adapt the existing ICS guidelines or to gain agreement to the development of local protocols at a future meeting of the Paediatric Intensive Care Society. The issue of clinical trigger points will be an even bigger challenge to the paediatric intensive care community.
- The current policy advising on whether potential organ donors should have a pregnancy test, and what steps should be taken if a potential donor is found to be pregnant, was written with heartbeating donors in mind. In view of the subsequent increase in the number of non heartbeating patients the policy needs to be reviewed. There is no need for a separate consent/authorisation form if the test is being performed for a potential organ donor. On the question of routine testing for pregnancy, information will be sought on how many units routinely test for pregnancy in controlled non heartbeating donation. Members felt that pregnancy testing of uncontrolled non heartbeating donors is not relevant. One arrangement should be agreed for both heartbeating and non heartbeating donors and intensive care units should consider testing for pregnancy on females of child-bearing age.
- DAG members endorsed a proposal that Dr Smith act as the formal representative for the Royal College of Anaesthetists on DAG.
- Although the consultation period for legislation on lasting power of attorney has now passed it will be possible to comment in writing to the Public Guardianship Office concerning the inclusion of a statement relating to organ donation. A paper outlining the relevant issues will be prepared for consideration at the next DAG meeting.

# Sweet success for a message of hope



**Sweet sensation: Members of the Live Life Then Give Life team with their Loveheart with a difference.**

The *Live Life Then Give Life* (LLTGL) campaign kicked off this year's National Transplant Week in style by constructing a 1m diameter Loveheart - the children's sweets that carry affectionate messages.

The awareness-raising event in Birmingham city centre was the idea and work of the LLTGL campaign, launched in 2006 by Emily Thackray and Emma Harris who both suffer from Cystic Fibrosis. Emily, Emma and the rest of their team know first-hand the life and death difference signing up for organ donation can make.

The idea arose after a discussion with Pete Wilcock, the owner of website Pimp that Snack, who is a keen supporter of the LLTGL campaign. Regular visitors to his website are encouraged to construct giant versions of everyday snacks. By teaming up, the hope was to attract attention to the Organ Donor Register and highlight the

benefits of organ donation and transplantation.

Aided by a generous supply of ingredients from Supercook and with backing from Transplants in Mind, the LLTGL volunteers set about constructing the unusual creation.

Amongst the fun, other members of the team were on hand to answer questions, provide information on how to become a donor and talk to shoppers about how organ donation and transplants had touched their lives.

Encouraging people to sign up were the Blue Watch from Ladywood Fire Station in Birmingham and Sparkles face-painting, who provided entertainment for visitors to the city-centre stunt. Loveheart brand owner Swizzels-Matlow also donated special packs of the sweets for the event, which gave people even more information about how to sign up to the Organ Donor Register.

A **memorial stone in remembrance of donors and their families** was unveiled in Cardiff's Alexandra Gardens in October.

The specially designed stone remembers the hundreds of donors and families who have generously helped give others a second chance through the gift of donation.

Made from local stone, the memorial has been ten months in the making and is jointly funded by local charities, including the Kidney Wales Foundation. The stone will be surrounded by a bed of Remembrance Roses, while opposite it there will be a bench where people can remember those who gave the gift of life.

"The memorial stone is a way of remembering those who have helped others through donation," said project leader Louise Collar, donor transplant co-ordinator team leader at the University Hospital of Wales.

"The idea for a memorial came about in January and a lot of hard work has gone in since then to make it a reality. The local council has been marvellous in its support, as have those who have funded the project and the donor families who formed part of a working party launched to manage it," she added.

Last year 51 donors from Wales helped save and transform the lives of others needing a transplant, while a further one in four people from the principality has pledged the gift of life and joined the NHS Organ Donor Register.

"Transplants help save so many lives every year, but this is only thanks to the generosity of donors and their families. The memorial stone is a wonderful way of remembering the gift of these people," said Roy Thomas, chairman of the Kidney Wales Foundation.