

bulletin

NHS

UK Transplant

The newsletter for everyone involved in organ transplantation and donation
Issue 48 Autumn 2003

In this issue: Ten-year plan for transplant services. World's first artificial intelligence model for liver matches. British team strikes gold in World Transplant Games. National Transplant Week. Bid to stop "transplant tourism." Black and Asian campaigns. Teaching pack for Scottish schools.



There have been complete changes to Ministerial appointments in England since I last wrote. However, both John Reid, Secretary of State for Health and Rosie Winterton, Minister for Health who has specific responsibility for transplantation had introductions to the importance of organ donation and transplantation very early in their new ministerial appointments. John Reid launched Transplant Week during his first week in post and Rosie Winterton published *Saving Lives, Valuing Donors – A Transplant Framework for England*.



UKT warmly welcomes the *Transplant Framework for England*. It sets out very clearly the Government's commitment to donation and transplantation and clarifies the role that the NHS, UK Transplant and the public and private

sectors can take in increasing organ donation. UKT has since issued the *UK Hospital Policy for Organ and Tissue Donation* to all acute hospitals in the UK. Co-ordinators will work with all acute trusts in their patch to discuss implementation of the policy in an attempt to ensure that all families are given the opportunity for donation. I am delighted that this has already struck a chord with some Chief Executives who are asking for presentations on the whole issue of organ and tissue donation for their Trust Board.

However, as I say repeatedly, there is much more to do. These policies are only as good as the people behind them working hard to ensure that they are integrated into practice and deliver real results. On that score current performance is just satisfactory but with noticeable and welcome improvements in the live kidney transplant rate. UKT continues to be grateful for everyone's hard work and support.

Sue Sutherland

Sue Sutherland
Chief Executive
UK Transplant

bulletin

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Front cover picture:

Pedalling together, Gareth Pons (left) aged 11 who is waiting for a kidney transplant, with cousin Kathy and brother Marcus, taking part in Bristol's "Life Cycle" bike ride as part of National Transplant Week (see pages 6-7) Credit: Barbara Evripidou/Bristol Evening Post

NEWS



Donor mother's plea

Rona Raphael (second right) joined forces with UK Transplant at the NHS Confederation Exhibition in June. Her message to NHS chiefs was that relatives who are not given the chance to donate are being denied the comfort that can come from knowing that, through their own tragedy, they have helped someone else to live. Rona's daughter Nicola died two years ago and Rona was not asked about organ donation. She approached hospital staff to carry out her teenage daughter's wishes to donate her organs after her death.

Saving Lives, Valuing Donors sets out key transplant aims

Saving Lives, Valuing Donors – A Transplant Framework for England is the Government's long-awaited ten-year plan for transplant services, launched in July 2003.

The framework sets out key aims for organ and tissue transplantation and describes good practice based on national and international evidence.

It states: "Our vision is of a patient and donor-centred service which achieves standards of excellence built on a genuine partnership between the public, charities, the NHS and commercial organisations – a partnership between those in need and those who can help."

The framework identifies the part the Government, individuals, the NHS and other stakeholders can play in:

- encouraging people to donate organs and tissue
- raising the quality and effectiveness of transplant services
- improving the clinical outcomes and quality of life of people who receive the gift of an organ or tissue
- increasing the supply of viable organs and tissue for transplantation
- accrediting tissue banks to ensure high-quality tissue for transplantation.



Rosie Winterton meets transplant patients at Guy's Hospital in London at the launch of the ten-year plan.

Its aims are to encourage the NHS, commercial, voluntary organisations and the general public to play their part in:

- ensuring at least 16 million people are registered on the Organ Donor Register by 2010
- developing a transplant service that respects the dignity of donors and is sensitive to the needs of donor families, friends and transplant recipients
- optimising the number of potential organ and tissue donors and the number of high-quality, safe organs and tissue for transplantation

- increasing transplant rates to save lives and improve the quality of the lives saved.

Health Minister Rosie Winterton said: "Organ and tissue transplantation is one of the major medical success stories of our time... our vision is of a society which values the benefits of transplantation, in which people are willing to donate and tell those close to them of their wish. We aim to provide a patient-centred NHS which values people and enables all those who wish to donate to do so, and provides first rate transplant services to make the best possible use of all donated

organs and tissue."

Saving Lives, Valuing Donors is at

doh.gov.uk/transplantframework

Ms Winterton MP was appointed Minister of State at the Department of Health in June 2003, and her responsibilities include transplants and organ donation.

Ms Winterton worked as a public affairs consultant and as the office manager for John Prescott's Westminster office before being elected Member of Parliament for Doncaster Central in 1997. Between 2001 and June 2003 she was Parliamentary Secretary at the Lord Chancellor's Department.

World's first artificial intelligence model for liver matches

An artificial intelligence expert from Finland has been recruited by a Birmingham hospital to devise a unique system to match up liver donors and recipients.

Yrjo Hiltunen will be adapting technology used in mobile phones to create the first programme of its kind in the world at the Queen Elizabeth Hospital in Birmingham.

It will rapidly process 80 different factors measuring the condition of both the donor and patient receiving the liver. This information will then be analysed in order to calculate the survival rate following transplantation.

By ensuring patients and donors are better matched, it is hoped that the system could provide a major breakthrough, ensuring more transplants are successful.

Liver transplant patient David Redwood, who has raised £24,000 for the department at the University Hospital Birmingham NHS Trust, which runs the Queen Elizabeth Hospital, has funded the initiative.

Doctors know that the success of a transplant depends on the health of both the recipient and the donor. But once a donor is identified, the organ must be transplanted within

hours, leaving doctors little time to complete a thorough assessment.

Currently, doctors match donors to recipients based on blood groups and the size of the liver.

Professor James Neuberger, consultant liver surgeon, said: "The programme has enormous implications if it is valid. Most systems for predicting survival are based on the condition of the patient. This will additionally consider the condition of the donor, as we know this has a very significant impact on the outcome.

"Once we are told a donor has been identified, we have a very short period of time to work in. For

example, we may be notified in the afternoon, the organ is retrieved in the evening and the transplant takes place at 8am the following morning."

Mr Hiltunen will spend six months at the Queen Elizabeth Hospital using neural networking – a component of the technology, which is used in mobile phones – to devise the new system.

The different factors under consideration include the age and gender of both the donor and the recipient, a wide range of laboratory tests and the intensive support required for both donor and recipient up to the day of the transplant.

Staff views sought on organ donation



In a wide-ranging study this autumn, healthcare professionals will be asked about their attitudes to organ donation.

Public research (see *Bulletin* Issue 47, Summer 2003) shows us that 90% of people support organ donation in principle but how do health professionals feel? The new research will give us a better understanding of views about organ donation amongst NHS staff – and if their professional roles have any impact on those views.

The researchers, Research Quorum, will talk to hundreds of staff in hospitals with and without transplant units. A wide range of people including chief executives, nurses, doctors, GPs, transplant unit staff, intensivists and support staff such as bereavement officers, receptionists and porters will be asked about:

- their views on organ donation
- how their work environment affects their views

- how they find out information about organ donation.

The research will build up a picture of attitudes amongst staff and the best ways to encourage positive feelings about donation. This will pave the way for an awareness campaign in 2004, which will hopefully increase staff support for organ donation. This could also result in more families being approached about donation and help increase donor rates.

Angie Burton, UK Transplant's Marketing and Campaigns Manager says: "It may sound strange but we really have no idea how the majority of NHS staff feel about organ donation. As individuals and as a workforce they are potentially powerful advocates for organ donation. This research will help us get a better understanding of their opinions and help us find the right way to encourage positive attitudes right across the NHS."

British team strikes gold in World Transplant Games

The British team took home more medals than any other country at this year's World Transplant Games in France in July. The team won an amazing 143 medals (for adult competitors): 62 gold, 39 silver and 42 bronze. Ranked second, the USA won 91 medals.

As many as 1,500 athletes, including 100 children, participated from 64 countries and the games were a real celebration of the success of transplantation. This is the first time that a junior team was entered from Great Britain.

Some of the British team

barely touched the ground as they flew back to the UK and then travelled on to Keele to take part in this year's British Transplant Games. More than 700 athletes, including 200 children, took part.

The British Transplant Games have been staged since 1978 in 13 host cities. Kaylee Davidson, a heart recipient, was the first child competitor in 1989 when she was just two years old.

Now 16, Kaylee competed in both the World and British Transplant Games. In France, Kaylee won a silver medal for ten-pin bowling

and a joint silver medal in the badminton doubles with her partner Hannah Swift – also a heart recipient from the Freeman Hospital.

Her mother, Carol, is the children's transplant team leader for the Freeman Hospital. She said: "Participation in the British Transplant Games is the ultimate achievement for these children. Whether they are first or last, it

Silver medal winner Kaylee Davidson.

simply doesn't matter – these children are all winners."



Photograph: Tony Colling, Sunderland Echo



Full speed ahead

Helen Mawdsley, who had a life-saving liver transplant just seven years ago, is being sponsored by UK Transplant in the New Era Novice, Open and Powerbike Championship.

UKT has provided Helen with a large tent emblazoned with giant organ donor card symbols as a team HQ, pit and organ donation information centre.

Helen said: "The tent is a real eye-catcher. I'm getting fantastic feedback from people and I'm hoping we can encourage thousands of race fans to talk about organ donation and join the NHS Organ Donor Register."

Brave Louisa made special mark on Transplant Week launch

This year's Transplant Week held in July, the thirteenth organised by Transplants in Mind (TIME), was a great success according to Sue Johnstone, TIME's administrator.

"The response" said Sue "has been really fantastic. Donor liaison nurses and transplant co-ordinators all over the country have organised events and the demand for publicity materials was far higher than any other year."

John Reid, the Health Minister, launched Transplant Week at the London Eye. Health officials, health professionals, transplant recipients and two special guests attended the event - Louisa Harrington, who was waiting for a heart, and Hannah Pudsey, who had a heart transplant in 2001.



Louisa Harrington with John Reid, the Health Minister, at the launch of Transplant Week.

Sadly, Louisa, who won affection and respect from so many of us, died at the end of July. Louisa was born with a defective heart and, after waiting for 13

months, had her transplant at Great Ormond Street Hospital but died following a difficult post-operative period.

At the launch of Transplant Week, Louisa had asked Mr Reid the simple but very important question – did he carry a donor card? Mr Reid had to admit he didn't, but he signed up to the NHS Organ Donor Register then and there.

During Transplant Week, awareness-raising events, that both celebrate the success of transplantation and stress the urgent need for more organ donors, were organised up and down the country by hospitals, transplant co-ordinators, charities, transplant patients, and families.

Freedom of Information

In line with all other public bodies UKT is adopting and maintaining a Freedom of Information (FOI) publication scheme.

This will be available on the website as well as in printed form by 31 October 2003.

For further information contact Judy Watt tel: 0117 975 7555.

Teamwork

The article in Summer Bulletin "After they've gone" was written by Magi Sque, Tracy Long and Sheila Payne.



One hundred white balloons were released at Royal Bolton Hospital on National Donor Day, as a tribute to all the people who have donated at the hospital. Little Alex Greenhalgh, whose mother Zoe died last year and donated her corneas, was the guest of honour, and he was heard to say: "They're all going to the stars to my mummy."



Outreach team helps promote Transplant Week

Helen Aldridge (above, second left), of Salisbury District Hospital, spends half her time as critical care outreach sister and half as donor liaison sister, so she was able to recruit the rest of the outreach team to promote Transplant Week along with staff from the Medical Admissions Unit.

Helen said: "We attracted a great deal of interest and we found that a large proportion of the visitors to the stands were card carriers but had not registered, which they were sent off to do!

"Several people returned on following days to inform us that they were impressed with the website, especially the facility to e-mail their wishes to friends."

Donor liaison sister training

A second UKT-organised training course was held during May and July for the ten new donor liaison nurses appointed in this financial year.

The training covered practical, theoretical, legal and ethical issues. This included learning to identify potential heartbeating, non-heartbeating and tissue donors; analysing and discussing the needs of the donor family and those caring for the potential donor; and investigating the ethical dilemmas involved in organ and tissue donation.

Fiona Wellington, Donor Transplant Co-ordinator Regional Manager at UKT, who organised the course said: "An important part of the course is all about networking. The course was residential and was a really good way for the nurses to get to know each other. They were a great group, who made lively contributions and asked lots of questions."

Royal stamp of approval

A set of commemorative stamps to celebrate the success of organ donation and transplantation is on the cards.

Royal Mail has included the suggestion on their list of possible stamp subjects for 2005, after being approached by Penny Hallett, UKT's Communications Director.

The idea is one of a number received by the Royal Mail to mark anniversaries, themes and events. The year marks the centenary of the world's first cornea transplant, the 40th anniversary of the first cadaveric kidney transplant in the UK and the 35th anniversary of the introduction of the organ donor card.

Penny said: "Royal Mail will now carry out market research involving focus groups and a telephone poll amongst a cross-section of the UK population to determine the potential popularity of organ donation and the other subjects on this list. A shortlist will then be drawn up and submitted to the Royal Mail Executive Board for approval following consultation with the Stamp Advisory Committee, an independent body. The selected designs are then submitted to the Queen for final agreement.

"We should know early in 2004 whether we have been successful."

Truckfest hauls in support

Scottish truckers drove home the message that organ donation saves lives at a weekend Truckfest in Edinburgh in August.

Chairman of the Scottish Truckers' Club, Gordon Sutherland, took the initiative and other club members have rallied round to promote organ donation.

Gordon said: "Truckers are big hearted people and I knew we could count on their support.

Truckfest is a huge event with thousands of visitors and the ideal time to talk to people about helping someone else. I put the donor campaign idea to the club members and everyone agreed to back it."



Have you ever thought that you could save someone's life?

Organ Donation. The Gift of Life.

As you read this more than 5,600 people are desperately waiting for an organ transplant. Transplants are one of the most miraculous achievements of modern medicine. But they depend entirely on the generosity of donors and their families who are willing to make this life-saving gift to others.

Every year nearly 400 people die while waiting for a donated organ and many others lose their lives before they even get on to the waiting list.

REGISTER NOW

But you can help. You can show you care. All you need to do is to think about whether you want to help someone else to live after your

NHS

UK Transplant

'More than 10.5m men, women and children want to leave a legacy of life for someone else'

[Will you join them?](#)



Companies adopt organ donation e-mail

Several large companies have used UKT's organ donation e-mail, specially designed to load onto company e-mail systems. At the simple click of a button staff can open up the e-mail and go directly to the registration form on UKT's website. The e-mail is cheap, easy to use and very effective. If you know a large organisation who might be interested in supporting organ donation this way, contact Angie Burton, UKT's Marketing and Campaigns Manager on 0117 975 7495 for details.

Huge rise in UKT website 'hits'

Visits to the UKT website continue to increase. The number of visits to the site was 46,720 during the quarter April-June 2003, an increase of 57% (up from 29,816) compared to the previous quarter. The maximum number of visits per day is over 1,300.

The "Sign me up" pages are receiving their fair share of visits, and several modifications have been made as a result of feedback from visitors. Over 2,000 people actually registered via the website during the quarter.

All the information from the old nhsorgandonor.net website has now been incorporated into the UKT site so please check that all the links you use are to the registration pages on the UKT site. The recommended link is:

http://www.uktransplant.org.uk/how_to_become_a_donor/how_to_become_a_donor.htm

Publications added to the website, in addition to the religious leaflets, include *Hospital Policy for Organ and Tissue Donation*, the quarterly Renal Balance of Exchange and annual points scoring poster for the national kidney allocation scheme.

We are always happy to encourage organisations to link to our website, with or without a reciprocal link from our site. We have standard text that can be used when a link is made. Please contact webmaster@uktransplant.nhs.uk for further information.

Vote for Life

New guidance recently issued by the Electoral Commission has dealt a blow to this year's Vote for Life campaign.

The Commission circulated a legal opinion to all councils suggesting that participating in the life-saving scheme risked breaching the Representation of the People Act. It suggested that inclusion of anything other than material relating to the electoral registration process could be unlawful.

Thirty-seven councils have told UKT that they feel unable to participate because of advice received from the Electoral Commission including 16 that withdrew having initially undertaken to run the full scheme.

Vote for Life was piloted in 1999. Last year it was the third largest source of new registrations to the ODR, with over 412,000 responses from 57 councils.

Black and Asian campaigns breaking new ground

UK Transplant runs several major campaigns as well as providing support where it can to local and regional promotional activities. A key target for 2003-04 is to get more black and Asian people to register on the NHS Organ Donor Register.

Black and Asian people are three times more likely to suffer from conditions that can lead to the need for a transplant but they currently represent less than 1% of people on the NHS Organ Donor Register. Two separate campaigns are running this year, specifically designed to encourage more people from each community to register.

Comedian Curtis Walker fronts the "Be part of the solution" black campaign for the second year running. Well-known and well liked by all age groups he is an effective advocate for more black people to register. Focused amongst the large black populations in London and the West Midlands, the campaign will feature:

- radio advertising on stations with many black listeners
- an "infomercial" on MTV Base, a specialist black music channel
- posters in hair salons, barber shops, hospitals, clinics, libraries, community centres, cafés and at grass roots roadshows
- an outdoor poster campaign in January and February 2004
- postcards distributed at cinemas in cities with large black communities
- newsworthy activity such as children's BBC (CBBC) regulars Devin and Reggie wearing T-shirts specially designed by fashion designer Wale Adeyemi and a record sleeve featuring



Photograph courtesy of the BBC.

Reggie (left) and Devin, CBBC Smile presenters, support the black campaign.

Curtis Walker sent to DJs to encourage them to talk about organ donation on air.

For the first time ever, the Asian campaign is visiting Asian festivals and melas around the country in an effort to tell more people about organ donation and the NHS Organ Donor Register.

Anjna Raheja from Media Moguls who are organising the stands at the melas says: "These grass roots, community events are a great opportunity to talk to Asian people about the issues facing them in more detail, answer their questions, give out leaflets in community languages and encourage more

people to register."

Later in the year the campaign will:

- visit freshers fairs at 12 universities around the UK with large numbers of Asian students and run promotions in student unions and at student events throughout the autumn and spring
- run specially organised nights at clubs popular with young Asian people in London.

If you want to find out more about these campaigns contact Angie Burton at UK Transplant.

E-mail:
angela.burton@uktransplant.nhs.uk

Bid for European legislation to stop “transplant tourism”

British MEP Robert Evans is calling for a ban on European citizens from buying organs abroad and prosecution for those that do. Buying or selling organs is banned in Britain, but over the past few years there has been increasing concern over “transplant tourism”, where people travel abroad and pay for organs outside the European Union.

Mr Evans, vice-chairman of the EU assembly's justice and home affairs committee, is involved in negotiations to draw up legislation in the European Parliament to close this “legal loophole”. Legislation would set out common rules and penalties for all EU citizens who attempt to buy organs both within the EU or elsewhere.

Proposals will be discussed and voted on in the European Parliament at the end of October, but not all member states are in support. Imogen Sudbury, Mr Evans's Parliamentary Officer, explained: “Although the UK is keen, some of the member states have reservations because they want to be able to fix their own penalties”.

In a memo to the European Parliament Mr Evans said:

// Trafficking in organs

Increasingly, reports are appearing in the media alleging that criminal gangs are trafficking, murdering and



Robert Evans MEP, who is working on legislation to stop transplant tourism.

even “breeding” human beings for their organs. These reports, while disturbing, are often sensationalised and there is little conclusive evidence about the extent and nature of the illicit organ trade.

“However, a number of serious studies indicate a growing problem in many parts of the world, especially in Eastern Europe, India and China. A recent Council of Europe report refers to the situation in Ukraine, Russia, Bulgaria, Romania and Georgia, where trafficking in organs appears to be extremely well organised and extremely mobile, involving a network of “brokers”,

qualified medical doctors and specialised nursing staff.¹

Transplant tourism

“On the other hand, the practice whereby wealthy patients travel abroad to developing countries to buy organs from living donors is well documented. Since the 1980s, the number of cases of ‘transplant tourism’ has continued to rise and further growth is expected as the demand for organs outstrips supply, and the internet makes it easy to identify potential donors. Although this type of commercial transaction is very different from the use of violence, fraud, threats or abduction to obtain organs, it still poses both moral and practical concerns.

“The removal of an organ from a donor living in extreme poverty, who has invariably been persuaded to give his or her consent by the false promise of a better life, can only be viewed as a gross violation of human rights and dignity. The health of the donor usually deteriorates rapidly after the operation, as does that of the recipient, who then represents an added strain on the medical service of his or her home country.

“Furthermore, there is clearly a link between ‘transplant tourism’ and organised crime, since it would be naive to suppose that a patient could identify and buy and organise the transplant of a matching organ without the help of a network of intermediaries and medical professionals.

National legislation

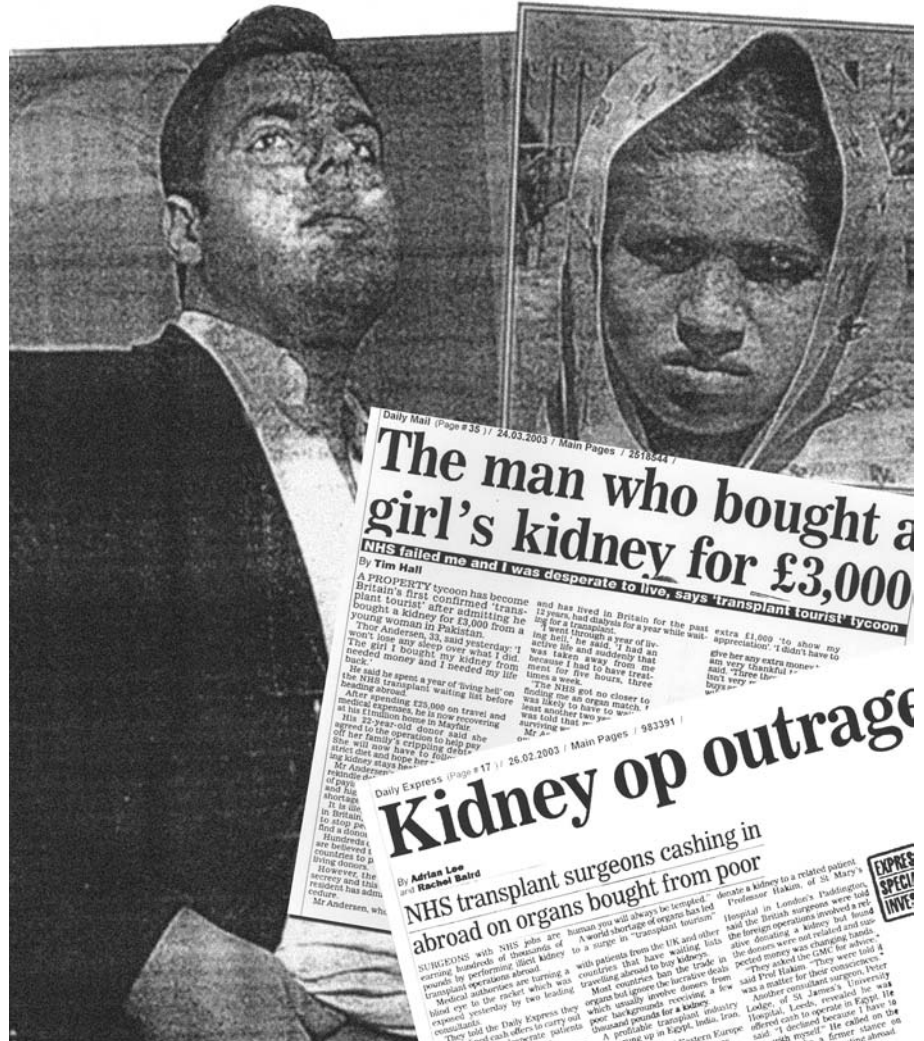
"Whilst organ trafficking is illegal in 14 out of 15 European Union member states, significant loopholes still remain. In all member states, with the exception of Austria, payment for organs beyond reasonable compensation is strictly forbidden. However, penal law in this area varies from country to country. Moreover, there is nothing to stop most European citizens from travelling abroad to purchase organs from living donors in countries where the practice is not illegal. Germany is the exception, having introduced an extra-territoriality clause, which makes it illegal for German citizens to purchase organs anywhere in the world.

Action at European Union level

"Currently, organised criminal networks are able to exploit the different legislation in member states and the forthcoming enlargements of the EU in 2004 and thereafter could potentially open a lucrative trading route. European level action is therefore urgently needed to harmonise the definition of related offences and the sanctions applicable.

"The Hellenic Republic has set out proposals for new legislation with common definitions of offences and penalties for criminal action. The proposals also introduce an element of extra-territoriality, so that individuals who seek to purchase organs from third country nationals, even outside the EU, would be committing an offence under EU law. //

Mr Evans hopes that new legislation will deter would-be transplant tourists and will also tackle the criminal networks and intermediaries involved. In a press release Mr Evans said: "Due to poor medical standards, inadequate nutrition and poverty in their countries of origin, donors' health inevitably deteriorates rapidly after the operation, forcing them either to live on dialysis for the rest of their lives or themselves begin the unending wait for a transplant in



far worse conditions. Urgent action is needed to stop this outrage to equality and human dignity."

He added: "Legislation can only be seen as one part of the solution. Transplant tourism is driven by the critical shortage in organs available and in order to tackle the problem it is essential to address its root causes...we must do more to raise awareness of the need for people to come forward as potential donors."

UK Transplant's recent national survey revealed that nine out of every ten people in the UK support organ donation in principle. Yet less than one in six people – 18% of the UK population – has registered their wishes on the NHS Organ Donor Register (ODR).

Although "transplant tourism" has been hitting the headlines it is not known how many people pay for transplants abroad. Earlier this year Thor Andersen travelled to India to

buy a kidney and he is the first British resident who has admitted publicly to doing this.

Last October, UKT contacted a number of kidney transplant centres to find out how many patients had presented following a kidney transplant outside of the UK. They were asked to report all cases from the past and to notify all future cases. The figures show that since 1974 a total of 90 people who had kidney transplants abroad are being followed up in the UK. The majority of patients told doctors that they had had their transplants in India (35) and Pakistan (16).

A report from the EU assembly's health committee: *Trafficking in organs in Europe* can be found at www.coe.int

¹ *Trafficking in organs in Europe*, Doc.9822. Report by Mrs Ruth-Gaby Vermot Mangold, Council of Europe. June 2003

New teaching pack being launched for Scottish schools

A new resource, *Organ Donation Teaching Resource Pack*, is being launched for use in secondary schools in Scotland this autumn.

The pack is designed for teachers to use in Personal and Social Education and Religious and Philosophical Studies. It has attracted strong enthusiasm and support from the transplant community.

John Forsythe, Chairman of Scottish Transplant Group, said: "The pack has been welcomed by teachers who wish to have a subject which demonstrates the value of discussion and informed argument in arriving at important decisions.

"It aims to inform young people about many of the subjects surrounding transplantation and it will allow them to make up their minds regarding these difficult issues. We also hope that they will extend the discussion to others within their families."

Scotland's Health Minister, Malcolm Chisholm, who launched the pack, said: "This is a remarkable

initiative. Scotland appears to be the first country in the world to develop such a resource pack for use in schools. All those involved in it should be very proud.

"Apart from its intrinsic value as a teaching resource, the development of this pack has the potential, in time, to create a generation who can make informed choices about organ donation. These materials have been specifically written to create awareness, impart information, and to encourage discussion on the ethical issues around organ donation and transplantation.

"It is then for young adults to make informed choices. Knowledge and information should also reduce any possible fears and confusions which may persist around these issues."

The Scottish Executive Health Department, UK Transplant and the British Transplantation Society have funded the pack. For a copy of the pack contact
jan.mcintosh@scotland.gsi.gov.uk
tel: 0131 244 2573

Living kidney donation study

Results of a two-year study to collate information on the practice of living kidney donation have been published. This study compared practice at all renal transplant centres in the UK and Ireland in 2000 and 2002.

The study found that there is widespread application of living kidney donation in the UK. Minimal access donor nephrectomy is offered at a small number of centres, but many have plans to introduce this into their practice.

The results showed that 27 (out of 28) centres performed living kidney donation in the year 2000, falling to 24 in 2002.

Consultants reported 356 operations were carried out in 2000, representing 19% of all kidney transplants, and 403 in 2002, representing 23% of all kidney transplants. Three centres offered laparoscopic donor nephrectomy in 2000, and five did so in 2002.

For further information contact:
Nicholas Brook, Division of Transplantation

The University Department of Surgery, Leicester General Hospital. E-mail:
nicholasbrook@fastmail.fm

Launch of heart transplantation booklet

A new information booklet about heart transplantation, aimed at patients and carers, is due to be launched in September 2003. The booklet gives information to support them through the transplantation process.

It has been produced by a project group of transplant nurses and co-ordinators representing the six heart transplant centres in the UK: Birmingham, Glasgow, Harefield, Manchester, Papworth and Newcastle.

Sharon Beer, Recipient Co-ordinator for the University Hospital of Birmingham NHS Trust, heart/lung transplant programme, said: "The members of the project group have been hugely enthusiastic and motivated. We have been working on the booklet for six months. It's a unique

collaboration and the publication is a 'first' in the UK".

Sharon explained that recipient co-ordinators and heart/lung transplantation nurses rarely have a forum to meet and network. She added: "We thought that putting together a generic handbook would allow representatives of the six centres to get together and share our individual experiences and also, with just six programmes nationally, consolidate our knowledge to enhance patient care."

The booklet will be available for distribution from early September 2003 via the six heart transplant centres and has a tailored foreword for each centre. It has been supported with an educational grant from Fujisawa Ltd (UK).

For more information contact: sharon.beer@uhb.nhs.uk

...David Mayer

David Mayer is a Consultant Liver Transplant and Hepatobiliary Surgeon at the Queen Elizabeth and Children's Hospitals in Birmingham.

Shortly after his appointment in 1990, he helped to introduce the technique of liver splitting, allowing one donor liver to be divided and transplanted into two individuals. Working with colleagues at Birmingham Children's Hospital he subsequently established the small bowel transplant programme.

He is currently Chairman of the Liver Advisory Group to UK Transplant, President-elect of the Section of Transplantation of the Royal Society of Medicine and Chairman of the Training Sub-Committee of the British Transplantation Society.

In April 2004 he is hosting the 7th Annual Congress of the British Transplantation Society at the International Convention Centre in Birmingham.

Q What prompted you to specialise in liver surgery?

A Chance and opportunism! I read mathematical physics at Sussex University before switching to medicine. One of my physics teachers was Professor Thompson – the guy who actually discovered the neutron whilst working with Rutherford in Cambridge. We asked what flash of genius had led to this discovery and he replied: "Any physics graduate could have done it. I just happened to be in the right place at the right time."

As part of my senior registrar rotation I was sent to work with Paul McMaster who had started the liver programme in Birmingham a few years earlier. This opened my eyes to a challenging new branch of surgery – I was in the right place at the right time and never looked back.

Q What else might you have done?

A I considered cardiac surgery. I was working as a cardiothoracic Senior House Officer (SHO) at Guy's when I first met my wife, Helen. The rota was one in two, operations went on until 10 or 11pm each night and the on-call SHO slept on the ITU. Helen put her foot down – little did she know...

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

A Patients in liver failure are transformed by their transplant. Many who return to the outpatient clinic are unrecognisable – they look

years younger. If you are looking for an "elixir of life" then a liver transplant is the answer.

Q What aspect do you least enjoy?

A We are forced to cancel elective operations at short notice, often in cancer patients, because liver transplantation takes priority.

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

A Development of a successful paediatric small bowel transplant programme. This was prompted by a child who was sent to Pittsburgh for a bowel transplant in the early 1990s. After careful planning, we established a team in Birmingham to provide a national service for the UK.

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

A Teamwork is crucial.

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

A Liver transplantation has developed into a routine procedure. We lose very few livers from rejection. Our major problem is to find enough donors to satisfy the increasing demand for transplants, especially with the current epidemic of hepatitis C. We now transplant livers from much older and less stable donors. When I started, we



only used livers from young donors, usually trauma victims, because older livers did not function so well. Improvements in road safety have reduced the number of trauma deaths which, of course, is good news – unless you are waiting for a transplant.

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

A I would get health service workers out of offices and on to the wards and other clinical areas. Many of our best nurses have been turned into full time managers and are out of touch with the "coal face". Senior medical staff combine clinical duties with management; senior nurses should do the same.

Q What is your most memorable moment?

A The first time I attended a donor operation. After we had brought the liver back and transplanted it into our recipient (a young man dying from fulminant liver failure) I realised the magnitude of the decision that the relatives had made – an unparalleled act of generosity.

Q How do you relax?

A I cycle every morning, read every evening and spend as much time with the family as I can.

Q What would you choose for your epitaph?

A He's in the right place at the right time!

Kidney and Pancreas Advisory Group

KPAG met on 14 May 2003

- KPAG representatives attended a British Transplantation Society two-day forum in June held to consider guidelines for immunosuppression.
- Paediatric patients – letters of non-compliance with the national Kidney Allocation Scheme will be issued to those centres transplanting patients as “easy to match” with non-favourably matched kidneys.
- A pilot scheme will be set up to trial the use of blood group A₂ kidneys in blood group B patients to improve the waiting time of blood group B patients. The trial should start in November 2003.
- National Transplant Database data collection – all centres will be asked to sign up to the agreed data set and to work with UKT towards electronic transmission of data within five years.

Patients' Forum

Patients' Forum met on 21 May 2003

- Members of the Patients' Forum now sit on each of the other advisory groups although it is still necessary to find a cornea representative for the Patients' Forum.
- As potential spokespeople, members were presented with an overview of the UKT media protocol and guidance.

UK Transplant Advisory Group

UKTAG met on 11 June 2003

- New terms of reference were agreed, the main change being to meet as and when necessary but at least once per year.
- Brain stem death testing – there is currently no national code of practice for management of non-heartbeating donors in ICUs. The Chief Medical Officer has been approached to recommend a review by the Academy of Medical Royal Colleges.
- Donation practice – members agreed a TCAG paper on the procedure for dealing with positive virology test results on potential donors. Members also considered whether all female potential organ donors of childbearing age should be tested for pregnancy. UKTAG concluded it was not necessary but that UKT should produce a protocol for national guidance.

Ocular Tissue Advisory Group

OTAG met on 25 June 2003

- Increases in corneal transplant numbers were noted although these are still well short of the activity levels of three to four years ago.

- The number of corneas issued but not used was reported and was consistent with figures for previous periods. The main reason for non-use was the recipient being unfit.
- Members noted a decrease in the number of corneas received by Bristol Eye Bank as UKT had been actively encouraged to send corneas to Manchester. However, the total number of corneas issued has increased despite fewer being received.
- Data relating to indications for graft – this information was agreed to be of a high standard and approaches are welcomed from surgeons in training if they wish to consider collaborative research with UK Transplant.
- Electronic data – a digital database has been developed based on UKT forms and discussion took place on piloting the software. Regional representatives agreed to raise the matter with their surgeons to check if they wished to take part in the pilot study.
- Members were asked to comment on a revised list of codes for the ordering of ocular material, which identifies the type of tissue required.

Organ Retrieval Working Group

ORWG met on 27 June 2003

- Length of time of the organ donation process – data was received from units on referral times to co-ordinators and variations in practice were noted. Further information on timing was requested to highlight where the problems are.
- Retrieval team – the principles of a self-sufficient retrieval team were discussed and the four integrated retrieval team models supported. This would potentially mean a team for Scotland, the North of England, the Midlands and the East, and the South. Further work needs to be carried out on problems with multi-organ retrieval and travel times.
- A document is being produced on the one-stage abdominal retrieval process, which will effectively become a multi-organ manual.

New allocation scheme for pancreata

A formal national allocation scheme for kidney/pancreas blocks and for pancreas alone has been introduced.

Until now there has been no agreed mechanism for offering on a pancreas that could not be transplanted locally. This scheme formalises sharing between centres, making access to pancreata more equitable and ensures that, where no local pancreas transplant centre exists, a

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New allocation scheme for pancreata

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pancreas can still be offered through UK Transplant's centralised system.

The scheme was agreed by the Kidney and Pancreas Advisory Group and ratified at the Renal Transplant Services Meeting in February 2003.

The scheme will work in the same way as that for allocation of livers for

routine transplant, ie the retrieving centre can retain the organ(s) for local use, but if they do not wish to transplant, the organ(s) will be offered to other centres in a priority order based on "balance of exchange" (in this case, pancreas exports minus pancreas imports), giving preference to centres who are net exporters. Offers will not be made for individual patients as in the Kidney Allocation Scheme; rather they will be made to a centre for use in a patient of their choice.

The current order of priority with regard to allocation of kidneys will be maintained. That is, that kidney/pancreas patients take priority over all kidney only patients with the exception that if two or more 000 mismatched children are identified for kidney only transplant, the kidney/pancreas operation will be called off wherever possible so that a child does not miss out on a 000 mismatched kidney transplant. Only if a pancreas cannot be transplanted as a whole

organ will it be offered first for islet transplantation and then for research (with appropriate consent).

The pancreas transplant centres involved are:
Addenbrooke's Hospital, Cambridge
Churchill Hospital, Oxford
Freeman Hospital, Newcastle
Guy's Hospital, London
Manchester Royal Infirmary
Royal Infirmary of Edinburgh
Royal Liverpool University Hospital
St Mary's Hospital, London

Diary

Second South West Transplant Symposium

23 - 24 September, St Mellion, Cornwall
Information:
sandra.brookes@phnt.swest.nhs.uk

7th International Xenotransplantation Congress

30 September - 4 October 2003, Glasgow
Information:
www.ix2003.co.uk

7th Annual symposium in Organ Donation and Transplantation

8 October, Manchester.
Organised by the Liverpool, Manchester and Leeds offices transplant co-ordinators.
Information:
Maria.Walsh@leedsth.nhs.uk

National Kidney Research Fund Conference

21 October, London
Predict and Prevent. Is this a new approach in renal care?
Information:
Vickiisaac@nkrf.org.uk

Skin Cancer in Organ Transplantation

6 November, London
Royal College of Physicians' conference.
Information:
kate@confcomm.co.uk

South West Transplant Regional Symposium

11 November, Plymouth
Covers increasing and maximising organ and tissue donation, controlled non-heartbeating donation, living donation.

Information:
sandra.brookes@phnt.swest.nhs.uk

Organ/Tissue Donation and Transplantation Study Day

12 November, Bristol
Aimed at health care professionals/allied professionals for Bristol/North Devon region organised by the Bristol Tissue & Transplant Co-ordinators.
Information:
tissueco-ords@bristol.ac.uk

National Paediatric Organ Donation and Transplantation Seminar

24 November, Nottingham
Information:
dcunning@ncht.trent.nhs.uk

4th Congress of the International Transplant Co-ordinators Society

29 November - 1 December
Warsaw, Poland
Information: itcs@online.be
Website: www.itcs.org

Open meeting of the UK Xenotransplantation Interim Regulatory Authority

1 December
Information: Jennie Mullins
tel: 020 7972 4824

VOICE RECORDER

TELEPHONE CALLS TO THE UK TRANSPLANT DUTY OFFICE

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

UK Transplant Emergency Contact Telephone Number

In the event of the main UK Transplant system failing, there is an alternative telephone number that can be used - 0117 931 4777.

During office hours this number will be answered by the UK Transplant receptionist but out of office hours the number is automatically directed to the Duty Office.

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

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We're in tune with festival

Becky Smith and Christian Brailsford, both donor liaison nurses, took an organ donation stand to the Glastonbury Festival. On reporting back, Christian was full of enthusiasm:

"Becky and I have both been to the festival before but this was probably the best one yet! Our stall had a great position in the Green Futures field with a constant stream of people passing by. Nearly 900 people came to the stall and 314 signed onto the NHS Organ Donor Register there and then. Most people were aged between 18 and 30 and told us they had always meant to register but never had the opportunity. So they were very glad to see us there!"

Becky and Christian distributed leaflets at other stalls and prompted the Muslim and Buddhist forums to debate organ donation. They became regulars on Radio Avalon, the festival station, talking about donation and put organ donation stickers on everything they could. However their *pièce de résistance* was a balloon release in front of the Pyramid stage during one performance. The balloons stayed on stage all evening and made a national TV appearance!

Tracey Dudley, former donor transplant co-ordinator, and Val Butler, a donor liaison nurse at Merthyr Tydfil, spoke on the role of the donor liaison nurse at the **International Transplant Nurses' Society**. Tracey said: "Our audience was predominantly recipient nurse based, so we were able to introduce them to the reasons for the need for donor liaison, the donor shortage, European strategies for improving donor rates, the importance of our donor families, and the need to identify and approach for donation."

Helen Challand, donor liaison sister at Royal Berkshire Hospital Reading, has been involved in **developing a non-heartbeating donor programme** (NHBD). Helen carried



Signing up at Glastonbury.

out a retrospective audit to highlight if there was any NHBD potential within the ITU then arranged teaching sessions for consultants and sisters to explain the plans of the programme and the principles of NHBD.

Helen recalls: "The teaching was met with a mixture of excitement and apprehension. However with more teaching arranged for both nursing and medical staff this apprehension soon turned to enthusiasm. So much so, that the first referrals came from wards and A & E, rather than the ITU."

Helen added: "The programme has really taken off in the last six months and there have been successful NHBDs from the A & E department, the ITU and one of the

oncology wards."

Helped by a crew of volunteers and a bevy of children, Helen Bradley, Donor Liaison Sister at Royal Preston Hospital, took part in a **Caribbean Carnival** in Preston. The team paraded the streets of Preston with giant donor cards and posters. Helen said: "We distributed thousands of leaflets, and raised £230 for Transplants in Mind (TIME). I can't thank the volunteers enough! It was good fun and hopefully the message of donation reached a lot of people."

In August, transplant and dialysis patients took part in a seven-hour **hike up Lochnagar** near Aberdeen to highlight organ transplantation. The event was organised by transplant co-ordinators at the Aberdeen Royal Infirmary and the Royal Edinburgh Infirmary and was led by transplant surgeon Mr Jetmund Engeset.

In June, kidney patients from the Queen Elizabeth Hospital, Edgbaston, celebrated **35 years of life-saving transplants**. More than 2,500 kidney transplants have been performed and thousands of people have undergone dialysis treatment at the hospital.



Leading the carnival procession in Preston.