In this issue: Should living liver donation be available on the NHS? Update on national potential donor audit. BODY marks its 20th year. Scottish study finds inequities in access to transplantation. Leave more than memories campaign extended.
This is an interesting time for the future of organ donation and transplantation as new legislation is taken through Parliament. The Human Tissue Bill is complex and UKT is receiving legal advice on its detail. At a later stage we will arrange detailed briefing/training for co-ordinators and others who need a detailed understanding of the legislation and its impact on practice. In the meantime I hope this update on the key points may be helpful.

The Human Tissue Bill currently passing through Parliament will repeal the Human Tissue Act 1961, the Anatomy Act 1984 and the Human Organ Transplants Act 1989. On becoming law, which may be in April 2005, it will apply in England, Wales and Northern Ireland. Scotland will shortly be consulting on proposals for their own legislation relating to organ and tissue donation which, it is anticipated, will follow the principles of the proposed English legislation.

The Bill makes it clear that consent will be required for the use of tissue and organs for any purpose. Consent will need to be “appropriate”. Where the person is alive, it means their consent. Where they have died, appropriate consent means their prior consent or, where there is none, the consent of their nominated representative or the consent of the person who was in a qualifying relationship with the deceased. The qualifying relationships are ranked in a hierarchical order and consent would be obtained from the person whose relationship to the deceased comes highest in the hierarchy.

We anticipate that the legislation will confirm that registration on the NHS Organ Donor Register or carrying a signed donor card will be evidence of appropriate consent from those who registered at age 16 or above (the issues for younger children are more complex and need further scrutiny). Where consent is apparent there will be no legal obligation to get the consent of anyone else and the donor’s consent cannot be overturned. However, the Act will be underpinned by a Code of Practice that deals with a range of issues including communicating with the family of the deceased, dealing with the situation of a family objecting to donation, and the consent of children under the age of 16. The new Human Tissue Authority will be responsible for the code but UKT would expect to have significant involvement in its development.

UKT’s legal advisors have confirmed that the NHS could be challenged for failing to comply with the consent of the deceased and, therefore, accessing the organ donor register to ascertain if consent has been given and for what organs will be increasingly important. The Bill has stimulated a further debate on presumed consent (opting out) in both the English and Scottish Parliaments. Given that new legislation was motivated by a need to improve public confidence following the Bristol and Alder Hey enquiries it is unlikely that a proposal for presumed consent will achieve significant support.

There is no evidence that presumed consent makes a difference to organ donation rates. When responding to Human Bodies/Human Choices the UKT advisory group made it clear that new legislation must build on the significant confidence already apparent in organ donation and transplantation services. UKT takes the view that presumed consent could, if a mistake was made, do much to undermine this confidence and adversely impact on the transplantation programme across the UK.

For more information about the Human Tissue Bill go to: www.doh.gov.uk/tissue/

Sue Sutherland
Chief Executive
UK Transplant

Front cover picture: Eloise Allen, who had a new “mismatch” heart when she was two years old, took to the wheel to help us in our “Leave more than memories” campaign.

Readers feedback
We’d like to know what you think about Bulletin. Please look out for the evaluation form with this mailing. Email us for an electronic version.
A new campaign, which is aimed at encouraging motorists to join the NHS Organ Donor Register, is being extended to run for a third month.

The “Leave more than memories” campaign, which is being run in partnership with the Driver and Vehicle Licensing Agency (DVLA) will now reach an additional three million drivers who are due to receive their vehicle tax reminders in April.

The campaign kicked off in January with specially designed registration forms encouraging drivers to “be remembered for life” sent to three million motorists. The owners of a further three million vehicles were mailed in March.

In just four weeks since the launch, more than 20,000 forms have been returned and the campaign has received widespread press coverage – in more than 100 newspapers and on 51 radio stations throughout the country.

In addition, calls to the Organ Donor Line are up from 300 calls per week to 900 and, to date, this level of activity has been sustained. The number of registrations via the Organ Donor Line has also jumped: from 100 per week before the campaign to 400 for three weeks, then settling down to 325 per week – still three times higher than the pre-campaign level.

Activity on the website has also increased with 37,700 visits during the four weeks from the campaign launch. This is up 75% on the previous month and up 329% compared to the same period last year. It is too soon to say how many people have signed up via the web during the campaign period.

The campaign is being backed by donor family charities, including BODY and the Donor Family Network, who have helped with numerous media interviews.

Once the final mailing has been completed UK Transplant will evaluate the three-month pilot with a view to extending the campaign to the drivers of all 30m vehicles in Great Britain. The evaluation will take into account the profile of organ donation through the publicity generated, the number of new registrations on the ODR and, most importantly, if there has been any effect on relative refusal rate.

If you would like to display a “Leave more than memories” poster. Email us at orders@uktransplant.nhs.uk
Update on national potential donor audit

The first six months of data of UK Transplant’s national potential donor audit (PDA) have now been evaluated and Kerri Barber, UKT’s Principal Statistician, describes the results.

Since January 2003, data have been and are currently being collected by donor liaison nurses in the 34 ICUs where they are in post, and by donor transplant co-ordinators and/or link nurses in all other units. An audit form developed in collaboration with other appropriate personnel is being used and one form is completed for each patient death in an ICU. All completed forms are returned to UKT for data input, validation and analysis.

An evaluation of six months of data (April-September 2003) has shown that at the time of analysis, 273 hospitals (347 ICUs) had reported at least one patient death. Of the 10,390 audited patient deaths, death was confirmed by brain stem death tests in 545 (5%) patients. In 64 (12%) of 545 families there was no record of any discussion of donation with relatives.

Of the 481 patients for whom the possibility of solid organ donation was known to have been suggested to relatives, consent for donation was given for 275 (57%) and not given for 206 (43%) patients. Of the 275 patients for whom consent for donation was given, 250 (91%) became deceased heartbeating solid organ donors.

Although this analysis shows that the overall relative refusal rate is 43%, there is considerable variability in this rate over time. The relative refusal rate for the first quarter (April-June 2003) was 48% and in the second quarter (July-September 2003) it was 37%.

Further analyses of the overall relative refusal rate by age, gender and ethnicity were performed. For age, the relative refusal rates were 40% for patients under 18 years, 34% for patients between 18 and 34 years, and 45% for patients over 34 years. The relative refusal rates for gender were 41% for male patients and 45% for female patients. For ethnicity, of 453 patients for whom data were complete, the relative refusal rates were 38% for white patients and 70% for non-white patients.

Further analysis of these data will indicate the extent of regional variation in the relative refusal rate and the reasons for families not consenting to donation.

In the meantime UKT hopes that the national PDA will continue to raise the profile of organ donation and heighten awareness of donation issues amongst all critical care staff. In addition, it will allow a realistic estimate to be made of the true potential for solid organ donation in the UK and will allow both local and national obstacles to realising the potential to be identified.

UKT is grateful to all those who are taking part in the PDA and to the Intensive Care Societies and Critical Care networks for their ongoing support of this audit.

For more information contact Kerri Barber:
Kerri.Barber@uktransplant.org.uk
Local media is on message

Word that readership of regional and local newspapers is on the increase came as music to the ears of UK Transplant Media and Public Relations Manager, Maxine Walter.

“According to a Newspaper Society survey almost 40 million adults – 84.5% of the UK population – now turn to their local paper to find out what is happening in their area,” said Maxine.

“This is excellent news as regional newspapers show a keen interest in reporting on organ donation and transplantation. Between July and September last year, we received a record number of cuttings – almost 500 – from 73 key regional daily newspapers – that’s 38 a week.

“Much of the coverage arose from UK Transplant news releases but case studies provided by many transplant co-ordinators, donor liaison nurses and charities helped achieve considerable coverage too, and a number of newspapers were inspired to run their own campaigns.

“It all adds up to demonstrate the effectiveness and potential of working with regional newspapers.”

During the same quarter, UK Transplant logged a further 330 stories and features from national newspapers.

Bury Council campaign takes off

Residents of Bury are being asked to make a special gift of life by joining the NHS Organ Donor Register (ODR).

Over 75,000 copies of the council’s free newspaper, Bury Metro News, have been distributed door-to-door throughout the borough. Each edition carries a story about the campaign and a freepost donor registration form for people to complete and return.

“We are delighted to back the NHS Organ Donor Register by launching this campaign and encouraging people across the borough to sign up,” says Cllr John Byrne, council leader.

“We have a responsibility to lead the community and are asking local people to consider making a straightforward commitment to helping others when they die. Registering is free and simple – and could help save someone’s life.”

The Council’s press and media team have worked closely with UKT and Fiona Wilkinson, Donor Liaison Sister at the Royal Bolton Hospital. This type of partnership working between the transplant community and local authorities has proved very successful at recruiting new registrants to the ODR.

UK Transplant has good links with many local councils throughout the country and will continue to develop new methods of co-operative campaigning to help reach even more people.

Rugby tackles organ donor shortage

The power of the press is very much alive and kicking in Rugby. A successful newspaper campaign has been running since October 2003 and, within 12 weeks of the launch, over 600 people had signed up to the NHS Organ Donor Register.

“Campaigns run on behalf of local people by local newspapers are becoming far more effective when it comes to influencing public opinion,” says Chris Smith, editor of the Rugby Observer.

U KT Chief Executive, Sue Sutherland, has thanked Rugby’s residents who “responded so magnificently to the appeal for more organ donors promoted by the Observer”.

Chris is still actively seeking other methods of getting the message across. “There’s been a surge of interest from local business wanting to stock organ and tissue donor leaflets in their reception areas.

“I’ve also touched base with the chief executive of the local council to see if he might be persuaded to send out organ donor forms with council tax bills.

“We’re delighted to be working on such a worthy cause.”
Co-ordination of tissue donation

During 2003 donor co-ordinators from UKT and the National Blood Service (NBS) worked on a joint project to explore all aspects of tissue donation and make proposals for improving the current arrangements.

One of the key drivers for this project was that tissue donation from deceased donors is currently organised in a disparate and fragmented manner across the UK leading to inconsistencies in patient care.

The project team concluded that significant improvements could be made and recommended that serious consideration be given to bringing all co-ordinators that work in the field of donation after death into one team in the longer term.

The chief executives of both organisations acknowledge the need for serious consideration to be given to amalgamating all tissue donor co-ordination services into a single service in the longer term. However, the immediate impetus for both organisations is to ensure that their own services work together formally and effectively so that tissue donors, families and transplant recipients receive a safe, high quality and consistent service based on jointly agreed standards and protocols that will aspire to be “world class”.

In response to this, NBS and UKT have convened a UKT/NBS tissue donation best practice group whose terms of reference include:

- producing joint standard national policies and procedures that detail the best practice processes and standards that should apply from the referral of a donor onwards through to the safe and effective retrieval of tissue
- establishing the training and development needs of donor co-ordinators and others involved in donor referral and advising on how this should be provided
- agreeing a joint strategy for public education and campaigns in relation to tissue donation
- making proposals about the data that needs to be collected, analysed and shared in order to ensure the delivery of a safe service
- reviewing progress and making recommendations about future strategic direction.

We are delighted that the group is to be chaired by Richard Bedford the acting Head of Tissue Services from the NBS and that there will be representation from Scotland and the British Association of Tissue Banking. Donor co-ordinators who will work on the group include Vicky Thornton and Jo Gregg.

We anticipate that this group will have a significant impact in addressing the issues outlined in the detailed report and will make a major contribution to immediate and long term arrangements that will improve care for recipients, tissue and organ donors and their families.

New comms assistant at UKT

In January Kate Baldwin joined UK Transplant’s Communications team as part-time Campaigns and Publications Assistant. In this newly created role she will be dealing with orders for leaflets and other campaign materials, supporting the company email and other campaigns and assisting with the production of Bulletin.

Kate joins us after a five-year career break during which she has been busy with her two young sons. Prior to this Kate was employed as Communications Officer with the National Association of Hospital and Community Friends in Colchester, Essex.

Kate can be contacted on 0117 975 7567 or Kate.Baldwin@uktransplant.nhs.uk

New UKTCA chair

Rachel Stoddard-Murden, transplant co-ordinator at Derriford Hospital, Plymouth, is taking over as the new chair of the United Kingdom Transplant Co-ordinators’ Association (UKTCA) from Helen Mandefield who has held the position for two years.

This is UKTCA’s 21st birthday year and there will be events planned throughout the year. The UKTCA Education committee is planning the AGM within a day and a half event with lively debates on contemporary issues. The event is planned for 9-10 June 2004 in Newcastle.

Rachel said: “I feel honoured to be able to represent the UKTCA and will endeavour to ensure the association gives a true reflection of all its members’ views. Thank you Helen for all your hard work.”
Transplant sailor back on the helm

Life is plain sailing again for kidney transplant recipient Stu Budden – a message he is taking to regattas across the country with sponsorship from UK Transplant.

Stu was diagnosed in May 2002 as suffering from end-stage renal failure. Now, after having a kidney transplant last September, he is embarking on a new sailing season with a Supernova sailing dinghy named Gift of Life.

The dinghy has been fitted out with a giant organ donor card on the mainsail to help him carry the message to racing events all over the country.

Stu is looking forward to a full season’s racing and promoting organ donation at the same time.

Stu said: “The boat, especially the mainsail, is really eye-catching. I’m getting fantastic feedback from everyone who has seen it so far – not just sailors – and I’m hoping we can encourage thousands of people to talk about organ donation and join the NHS Organ Donor Register.”

We must have patients’ consent

UK Transplant is planning to start a pilot consent scheme in eight transplant units at the beginning of April 2004 to test procedures for obtaining explicit consent from patients for the use of their personal data by UK Transplant.

This is a requirement of the Patient Information Advisory Group and UKT aims to run the pilot scheme for nine months before rolling it out to all transplant units next year.

A working group, with representation from UKT’s Patient’s Forum, the UK Renal Registry, Scottish Renal Registry and the Royal College of Surgeons, is developing the procedure.

Explicit consent for use of their personal data is being sought from potential transplant patients and living donors.

The units involved in the pilot are the renal units at Edinburgh, Birmingham, Belfast and Oxford; the liver units at Leeds and Cambridge; and the cardiothoracic units at Harefield and Wythenshawe.

For more information contact Judy Watt. Tel: 0117 975 7555 Email: Judy.Watt@uktransplant.nhs.uk
Renal NSF to provide better kidney care

New Department of Health guidelines setting standards for kidney dialysis and transplantation in England have been welcomed by Sue Sutherland, Chief Executive of UK Transplant.

Sue said: “The emphasis on the importance of transplantation is welcome. This framework should be used as an enabling document to maintain and increase investment in organ donation programmes so that each year more and more people benefit from a kidney transplant.”

The document, Renal Services National Service Framework, is the first of two parts, and sets out a modernisation plan for dialysis and transplantation that puts patients at the centre of care. It lays out five standards of care that health services must meet by 2014.

The second part of the framework, yet to be published, will deal with prevention and end-of-life care.

The NSF outlines the development of renal networks where staff will work across traditional boundaries to provide seamless, integrated care to patients. The networks are intended to enhance clinical outcomes, provide more equity of service provision, and improve patients’ experiences of treatment.

Early action, by 2006, will include a national survey of services, expanding haemodialysis capacity, and giving every patient the choice of the type of dialysis they receive.

For more information see: www.doh.gov.uk/nsf/renal/index.htm

Five key standards in the Renal Services National Service Framework

• Improved access to information and increased involvement of patients
• Early preparation for dialysis to minimise complications and progression of the disease
• Fast, effective surgery for those with established renal failure in preparation for dialysis
• Services designed around patients’ needs which provide opportunities to interchange between different types of dialysis
• Improved access to and outcomes of renal transplants

Be part of the solution

The drive to encourage more black people to think about organ donation continued this spring with a poster and radio campaign targeting London and the West Midlands.

There are over 450 black patients currently waiting for a transplant, more than 6% of the UK total. Since the campaign launched in April 2002, over 600 black people have joined the NHS Organ Donor Register.

The poster campaign, featuring comedian Curtis Walker, has been running mainly on Adshels (bus shelters) in specifically targeted areas with high black populations. Posters have been placed in barbershops and other community and health outlets, and postcards have been distributed to cinemas.

A supporting radio campaign has been run on Choice FM, Kiss FM, BRMB and Galaxy stations, targeting black listeners of many ages, mainly on music shows.

Boots the Chemist is helping by stocking the leaflet What every black person needs to know about organ donation in London and West Midland stores.

Advertising campaign launch in Scotland

Malcolm Chisholm, the Scottish Health Minister, launched a major advertising campaign in Scotland in February.

The campaign implements a key recommendation of the Scottish Transplant Group’s Organ Donation Strategy for Scotland. Headed “Organ Donation, Have You Talked About It?”, it consists of radio, newspaper and milk carton advertising.

Speaking at the launch Mr Chisholm said: “The main message of the campaign is encouraging people to discuss their wishes with their loved ones.

“It is essential to get the message across that, as well as carrying an organ donor card or being on the NHS Organ Donor Register, people should talk about their wishes with their loved ones.”

Posters are up in barbershops.
Plans are already underway for this year’s National Transplant Week, the 14th organised by charity Transplants in Mind (TIME), and supported by UK Transplant.

TIME is pulling together a listing of events that are being organised by transplant co-ordinators, donor liaison nurses and volunteers all around the country in order to maximise the publicity for the week.

So, whether you are planning a sponsored walk, a balloon release, a stall in your local superstore, a photocall with a local MP or celebrity, or will simply be distributing leaflets: please get in touch with TIME.

Sue Johnstone, TIME’s co-ordinator, said: “This is a really good time to organise local events to raise awareness of the NHS Organ Donor Register and create some proactive media stories.

“We want to hear about events that are planned around the country as early as possible so that we can gain as much publicity for organ donation as we can.”

TIME is also co-ordinating its 150 volunteers to get a National Transplant Week poster and supply of registration leaflets into as many GP surgeries, local pharmacies, libraries and schools as possible.

The transplant team at Derriford Hospital in Plymouth have been planning well ahead for National Transplant Week and have negotiated some great publicity opportunities with local bus and ticketing companies.

When they found they couldn’t book the Donor Bus they decided to contact the local bus company, Plymouth City Bus, to try to get them to run advertising on National Donor Day. To their delight they managed to negotiate not one day of advertising, but three months of free advertising on the sides of ten buses!

Their ideas then started mushrooming. They are arranging to have adverts printed on the back of 300,000 bus tickets during National Transplant Week and on 15,000 books of Tamar Bridge tickets for six weeks in June and July.

Marie Roy, Donor Liaison Sister, and Lynne Hamilton, Transplant Clerk, have been working hard to make all these ideas happen. Marie said: “When we couldn’t get the Donor Bus, we just started coming up with other ideas. We started making some phone calls and it all snowballed. Everyone we’ve approached has been really positive and receptive to our ideas. It was just a matter of making that first call!”

During National Transplant Week itself the team will be out and about at a number of different sites. Their main focus will be Plymouth city centre where they hope a local college band will perform free of charge throughout the day and they plan to give out helium-filled TIME balloons, which will be paid for by a local card shop.

The team have negotiated free advertising for all these schemes and UKT is helping out with design. The team is also working with the hospital press office and local newspapers to maximise publicity.

For more information about the team’s plans contact Lynne Hamilton, Transplant Appointments Clerk 01752 517717 or Marie Roy, Donor Liaison Sister, email: Marie.Roy@phnt.swest.nhs.uk
NEWS

New duty office manager

Neil Stapleton hit the ground running when he took over as the new Duty Office Manager at UKT in January 2004. Neil has worked at UKT as the Database Team Leader in Data Executive for five years, with a brief spell away with South Gloucestershire Council working in performance management.

In his role in Data Executive, Neil worked on the quality of data and data validation and now he feels privileged to be able to step back and take a look from a duty officer point of view.

Neil commented: “I’m now working at the forefront of organ allocation after spending much of my time, previously at UKT, looking at post-transplant clinical follow up. I’ve been lucky enough to see the transplantation picture from start to finish.

“My immediate challenge is getting to grips with the clinical information – learning about the organ allocation schemes and contributing to the advisory groups.”

Neil is awaiting the full outcome of the potential donor audit (PDA) with interest. He said: “Preliminary results indicate that there is an unexpectedly low consent rate. I know there is substantial work being undertaken to improve donation rates. Obviously this would have a direct bearing on the number of donors handled by the duty office and I look forward to embracing this new challenge.”

Neil is planning visits to transplant centres and looks forward to meeting as many donor co-ordination staff as he can. In the meantime he welcomes any comments on the service that the duty office provides.

He can be contacted on tel: 0117 975 7584 email: Neil.Stapleton@uktransplant.nhs.uk

Papworth’s transplant jubilee

This year Papworth Hospital marks a quarter of a century since its first transplant operation on 14 January 1979 by Sir Terence English. Since then the Cambridgeshire hospital has gone on to lead the way in heart and lung transplantation in the UK.

Now patients can expect to live an average of over ten years, and Papworth’s longest surviving heart transplant patient had their operation 24 years ago.

“We’ve come a long way since the first heart transplant,” explains Professor John Wallwork, Papworth’s Director of Transplant Services. “This is a landmark year for us. Not only have we been performing heart transplants for 25 years, we will do our 1,000th heart transplant operation and will be celebrating 20 years of heart and lung transplants.

“We really want to celebrate the work we have done, but also use this landmark to promote and encourage as many people as possible to consider registering as an organ donor”.

The hospital is planning a scientific meeting in June that will bring together heart and lung doctors from across the world as well as members of the original team.

Health Secretary, Dr John Reid, has accepted an invitation to attend the day’s activities.

Other activities being organised are the planting of 25 trees, 25 recipes for healthy hearts and an exhibition of 25 hearts drawn by celebrities. There are also plans for an exhibition of the work of the hospital’s resident artist, Jane Prophet, who will be working with transplant patients and staff.
International non-heartbeating donation conference preview

An international conference on non-heartbeating donation is being organised by King’s College Hospital in May. It will bring together some of the world’s leading experts in the field, to share good practice and advance international understanding. Here, Paolo Muiesan, Heather Tollerton and John Richardson, the organisers of the conference, give some background to non-heartbeating donation.

During the past decade, as a response to the shortage of organs for transplantation, there has been renewed interest in non-heartbeating donation. Following the successful long-term results with the use of kidney grafts from non-heartbeating donors (NHBD) for transplantation, recent but limited experiences have also been reported with liver, pancreas and lungs.

The enthusiasm around this growing practice stems from the shortage of organs available for transplant. In addition non-heartbeating donation is seen as a positive option for potential donor families, who would otherwise be unable to donate.

Non-heartbeating organ donation may be controlled or uncontrolled. Controlled non-heartbeating donors are patients who have suffered an irreversible brain injury but do not meet brain stem death criteria and in whom the decision to donate follows the one to withdraw treatment within the critical care unit.

In uncontrolled non-heartbeating donation, organs are donated after the patient experiences a sudden cardiopulmonary arrest and death is declared after resuscitation attempts fail to restore cardiac function. The patient may arrive at the emergency room in arrest or may suffer an unexpected arrest while in hospital.

It is now established that long-term patient and graft survival after kidney transplantation does not differ whether the organ comes from a non-heartbeating or a brain stem dead donor. Early reports of liver transplantation from uncontrolled non-heartbeating donors revealed a high incidence of primary graft non-function and vascular complications. The shift in use of controlled non-heartbeating donation and an increasing experience in donor selection have, however, led to a significant improvement in outcome. Primary non-function and graft survival rates are now comparable to those of recipients of liver grafts from heartbeating donors.

There are many exciting developments in non-heartbeating donation. Non-heartbeating lung and pancreas transplantation programmes are becoming a reality. In the near future cell transplantation from non-heartbeating livers and pancreatic islets will develop. In addition, new techniques of extra-corporeal organ perfusion, preservation and conditioning of organs are being experimented with. It is hoped that this will minimise the ischaemic damage, help select transplantable organs and improve the quality of non-heartbeating grafts.

Renowned surgeon retires

Jetmund Engeset, celebrated transplant surgeon at Aberdeen Royal Infirmary, has retired after over 30 years at the hospital. Mr Engeset founded the Kidney Transplant Unit in Aberdeen in 1975 and has led transplant surgery in the area for three decades.

Mr Engeset has seen huge developments in transplantation surgery over that time.

“Having seen the results improve from 50% survival to 90-95% is great. The sad thing is that the number of transplants has fallen,” he commented. And on his retirement he said: “Of course I’ll miss work, but now I’m well past my sell-by date!”

In addition to his commitment to transplantation Mr Engeset has also contributed enormously to the availability of organs within the Grampian region. He was always readily available to speak to relatives or encourage colleagues on organ donation. The unit in Aberdeen closed at the end of last year and patients now travel to centres in Edinburgh or Glasgow.
RESOURCES

UKT has produced new pull up banner stands for donor transplant co-ordinators throughout the country. The new stands will help with publicity and awareness-raising work. They have been produced in three different designs and are easy to put up and to carry.

Following the success of our snowman sticker, and requests from many of you, we have produced three more sticker designs. These can be used throughout the year on letters, envelopes or as lapel stickers. They have been widely distributed to transplant co-ordinators, donor liaison nurses and to partner charities and other organisations.

UKT has produced a new religious leaflet Organ donation and religious perspectives to organ donation which summarises the information contained in the existing series of six leaflets. This leaflet has been produced as a response to demand from members of the public. The new leaflet has been written by Rachel Howitt (whose contract with UKT has now finished) in co-operation with key religious leaders. It is available in English only.

New A4 folders and pads are also available from UKT, bearing the straplines “Transplants save lives” and “Organ donation. So life can go on.” These have been produced for study days and other appropriate events arranged by transplant co-ordinators and donor liaison nurses.

For more information about any of these resources contact Nicole Sutherland. Tel: 0117 975 7490 or email: orders@uktransplant.nhs.uk

The new pull-up banners and, right, the new stickers.

New promotional resources from UKT

UKT web update

A major addition to the site is the “Publications” section of the newsroom which, on a single web page, provides shortcut links to all of the Authority’s publications. All the fact sheets (also in the newsroom) are being updated with new financial year statistics and an additional one on the cost effectiveness of transplantation has been added.

The document describing the Authority’s stand on the informed/presumed consent debate has been updated as new information about the Human Tissue Bill becomes available (under policy and statements in the newsroom).

Finally the general statistics section has been updated with validated activity statistics for the calendar year to the end of December 2003.

Heart posters and information

The Children’s Heart Federation runs a telephone help line and other support services for families of children with heart disorders. They have produced an A4 poster, publications list and information sheet detailing the services they offer. These can be ordered from them or downloaded from their website. Tel: 020 7820 8517 www.childrens-heart-fed.org.uk
Inequities in access to transplantation

A study in Scotland has found that women, older people and those who are socially deprived are less likely to be placed on the kidney transplant list compared to other patients. Once listed elderly people and diabetics are less likely to receive a transplant. Mr Gabriel Oniscu, Specialist Registrar at the renal transplant unit at the New Royal Infirmary of Edinburgh and member of the research team, details the key findings.

The number of patients referred for transplantation has increased dramatically, the demand outstripping the supply. This has brought to the fore the issue of equity of access and there is growing evidence from transplant programmes that inequalities in access to transplantation services exist.

The study, led by consultant surgeon John Forsythe, investigated a cohort of over 4,500 patients starting dialysis in Scotland between 1989 and 1999 following them to listing, transplantation and beyond.

Getting on to the list

Overall, 38% of all dialysis patients were listed and only 24% received a kidney transplant during the follow up period (11 years). The analysis revealed significant disproportions in access to the renal transplant waiting list and renal transplantation based on various socio-economic and geographical factors.

The research revealed that elderly patients, female patients and socially disadvantaged patients were less likely to have access to the transplant waiting list. An interesting finding was that the centre of referral played a significant role. Patients starting dialysis in a hospital with a transplant unit attached had better access to the waiting list than those receiving dialysis in a hospital without a transplant unit. Another finding, based on geographical criteria, was that patients living furthest away from hospital were more likely to be placed on the waiting list than those living closer. In addition, patients with diabetes leading to renal failure were the least likely to be listed for transplantation.

Once a patient is on the waiting list, age and primary renal disease remain the main causes of differences in access to a kidney graft, with elderly people and those with multi-system disease and diabetes leading to renal failure being least likely to receive a graft. Similar differences in access to transplantation were noted in other systems but, unlike most of the results published so far, most of the inequities noted in Scotland disappear once the patient is listed.

Why are there differences?

The findings of this study are important for the transplant community, and similar inequities may exist elsewhere considering that the management of renal failure and the transplantation process are similar throughout the UK. They are also important for the patients, for whom access to the service may be the greatest hurdle. Although some of the differences were expected, in particular with regards to age, explanations for other, such as gender or social deprivation, were difficult to find.

It can be argued that comorbidity plays an important role in the inequities noted, but evidence from elsewhere indicates that it does not completely alleviate the effect of sociodemographic factors. However, the effect of the comorbid conditions could not be properly assessed in this study because of insufficient data, but it is undoubtedly worth exploring. This would be greatly facilitated by a more comprehensive data set collected by the renal and transplant registries and interlinking the information stored.

Another important issue noted in this study was a significant centre difference with regards to access to the waiting list. This illustrates that there are potentially different listing practices across the country and may indicate a different weight given to various comorbid conditions – an important point that needs to be further investigated.

Exploring an alternative assessment process

Perhaps the UK clinical practice guidelines for evaluating candidates for renal transplantation (revised by UKT’s Kidney and Pancreas Advisory Group in 2003) will help in eliminating these differences. Last, but not least, as the number of patients referred for transplantation increases, this research has highlighted the need for a rigorous assessment process and an evidence-based method of identifying patients for whom transplantation is unlikely to provide a significant survival advantage over dialysis. Such a method, which will allow the identification of suitable transplant candidates, based on their general status, comorbid conditions and expected survival on dialysis or transplantation as predicted by a mathematical model, is currently being explored.

Details of the study have been published in the BMJ, volume 327, 29 November 2003.

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LIVING LIVER DONATION

Living liver donation is not available on the NHS. However, with the critical shortage in livers available for transplantation, should we be addressing this issue? James Neuberger, Professor of Hepatology at the Queen Elizabeth Hospital Birmingham, considers the option of living liver donation and the ethical dilemma it poses.

The last few years have seen some expansion of the donor pool. There are several reasons for this; surgical advances have allowed, in some cases, donor livers to be split so that the larger right lobe is given to a larger recipient and the small left lobe to a child; greater understanding of risk factors has allowed use of some marginal livers and use of donors from some non-heartbeating donors will add to the pool of liver grafts. The Government too has played its part by increasing resources to develop new strategies to improve donor rates.

However, despite all these initiatives, the number of donor organs is insufficient to meet the existing demand.

Living liver donation

S Raia and colleagues in South America did the first living liver donation in 1989. The first operations were for children and the incentive for this was the increasing mortality amongst children on the transplant list. The left lateral segment was taken and implanted in to a child.

Subsequent surgical and anaesthetic development has allowed the technique of living liver donation to be applied to adults. However, for a transplant to be successful, a minimum volume of liver has to be transplanted. It is estimated that the minimum ungrafted donor weight ratio is 1%. For most adult recipients, the larger right lobe has to be taken.

Current activity

Only a small number of privately financed living liver transplants have been undertaken in the UK, pioneered by the team led by Professor Roger Williams and Mr Nigel Heaton. In the UK in 2002, there were 695 liver transplants from deceased donors and six transplants from living liver donors.

These figures contrast with data from the United States where the figures are larger. In the calendar year to the end of June 2002, there were 5,486 liver transplants, of which 303 were from living donors. The proportion of living donor transplants is higher in the US than in the UK. However, the number of living liver donations in the US has decreased from the previous year. These figures represent, over the previous year, an increase of 8% in the transplants from cadaveric donors but a fall of 37% in living liver donation.

Concerns about living liver transplantation

The major concern with living liver donation is, of course, the risks to the donor. A healthy volunteer is asked to undergo a hazardous procedure, which is of no physical benefit (although clearly there is a psychological benefit).

There is a lack of solid information on which to estimate the risk but current evidence suggests that the risk of death to the donor of a right lobe is between 0.5 and 1% (between one in 200 and one in 100). There is also a risk of other complications such as a bile leak, wound infection and so forth. It must be emphasised that the risk of removal of the left lobe is considerably less and may be in the order of 0.1% (one in 1,000).

These figures compare with estimates for the risk to living kidney donors, where the risk of death is 0.03% (one in 3,000) with a 2% (one in 50) risk of major morbidity.

It is not yet possible to say what the long-term benefits and risks are to the donor.

Ethical considerations

There remain concerns as to whether living donation should be accepted on ethical grounds.

On the one hand, it can be argued that a well-informed donor has an absolute right to determine whether he or she will give tissue to benefit a recipient, be they related by blood, family connections or indeed whether they should be able to give

Developments in Scotland

As the debate on living liver donation continues in England and Wales, Scottish surgeons are starting discussions as to whether a programme should be considered in Scotland. Faced with the critical shortage of donors, the Scottish Liver Transplant Unit in Edinburgh has submitted a bid for funding a live donor liver programme.

The Scottish Transplant Unit has had initial discussions with the Scottish national funding body. After submitting a final bid it hopes to hear it can consider the surgery in the next few months.

John Forsythe, lead clinician at the Edinburgh unit, said: “Live donor liver transplants is not something we go into lightly. But in the UK there is a critical organ donor shortage.”

An advocate team would be set up to ensure donors are medically and psychologically suitable. The team would include a consultant psychologist, an independent medical assessor, unconnected to the transplant unit, a social worker and a transplant co-ordinator.
The average waiting time for a liver transplant is 70 days, but many have to wait up to two years.

part of their body to anyone if they choose.

In this case, society, whether the government, the courts or professional bodies, has no right to obstruct such an altruistic decision. If this view were accepted then guidelines would need to be drawn up to ensure that the donor receives all the information required to make a well-informed decision and that the healthcare professionals involved ensure that the donor is not only well-informed but able to make a rational decision.

However, it could also be argued that an individual's right may be curtailed for the benefit of either society or the individual: for example, drivers are obliged to wear seat-belts in cars, motorcyclists have to wear safety helmets.

Doctors have a moral and ethical obligation to act in an individual's best interest and what constitutes the best interest is arguable. What is the best interest may differ whether the recipient is a child or an adult not only because the risks to the donor will depend on the amount of liver taken but also there are different ethical dimensions. Furthermore, it may be that the risks to the donor have to be balanced against the risk to the recipient.

A second consideration with living liver donation is whether the indications to be a liver recipient of a cadaveric donor should be the same as for a living donor. The UK guidelines state that transplantation should not be done unless there is a greater than 50% chance of survival after five years.

The survival criteria are designed in part to ensure that people who are listed for transplantation have a realistic chance of receiving a liver in time. Thus, for example, a patient with a large hepatocellular carcinoma in a cirrhotic liver may have a one-year survival probability without a graft of less than 5% but, after transplantation, the five-year survival probability may be, say, 30%. Although there would be a clear survival benefit for that patient to get a graft, the patient would not meet the criteria.

The argument over extended indications continues and has not been fully resolved. Whilst there needs to be a clear balance between risks to the donor and benefit to the recipient, healthcare professionals have a duty to both parties.

Should living donation be available in the UK?
The fall in living donation seen in the United States is probably the consequence of adverse publicity following the death of a donor in New York.

It is, however, unrealistic for the public to expect that living liver donation is entirely safe. However expert the surgeons and supporting team are, liver resection remains a major procedure and is inevitably associated with morbidity and mortality.

The public needs to be educated to expect such an outcome although, of course, assurances need to be in place that as ever, all patients receive optimal care.

I believe that there is a need for public debate in the UK to see whether living liver donation should be available now on the NHS.

On the one hand, it can be argued that the relatively low mortality and morbidity of people on the transplant list is such that the current supply of cadaveric donors is adequate and resources should be focussed on maximising the use of potential donors.

On the other hand, the increasing mortality of people with liver disease and the 10% mortality on the transplant list is such that in selected indications, living liver donation is required.

If living donation becomes available in the NHS, additional resources will be required and the public will need to be educated as to the implications and risks to the donor.

Transplant units will need to put in place robust mechanisms to ensure that potential donors are assessed properly both from the physical and psychological point of view and any form of coercion, implicit or explicit is mitigated as far as possible. Once living donation becomes an available option, it will not be possible to prevent some form of implicit donation.

Only when there is universal agreement that living liver donation is required in the UK to be available on the NHS and when procedures can be agreed publicly, should this development occur.
This year transplant charity BODY – the British Organ Donor Society – celebrates its 20th year.

John and Margaret Evans set up BODY in February 1984 following the death of their son, David, as a result of a road accident. After his death they felt isolated. They decided they wanted to help other families but their search for a support organisation proved fruitless.

“We soon found that not only was there nothing for donor families, but little emotional support for most recipients,” said John. “Our resolve to do something was crystallized by a story in the paper of a mother wandering round the hospital at night trying to decide about organ donation. We could at least be there for such families.”

They aimed to offer emotional support and information to families and their plans were to start quietly and locally. However, there was such great media interest that, within a week, they had received 600 letters: some were even from outside the UK.

The vast majority of time in those early days was spent listening, befriending and providing information for donor families. But they soon realised that recipients were also suffering emotionally, perhaps feeling guilty that someone had died to give them their new lease of life. John and Margaret could reassure recipients that the knowledge of donation was often the donor family’s one source of support.

Today BODY has supporters from both donor and recipient families and campaigns tirelessly to promote organ donation. Their activities include providing speakers and information displays and support for NHS professionals and educationalists as well as the public.

BODY has produced a series of information booklets entitled Gift of Life and has lobbied hard to get transplantation into the school curriculum – it is now listed as a recommended topic for discussion under Citizenship.

With funding from the Department of Health, BODY has taken a “roadshow” into schools, colleges and community groups. The roadshow consisted of talks, exhibitions and discussion aimed at 11-18 year olds and was tailored to fit different aspects of the curriculum. Although this project has now ended, the talks developed for the roadshow are available as a resource for teachers from the BODY website.

With lottery funding BODY has also commissioned research from Southampton University into the experiences of bereaved adults who had been asked about organ and tissue donation. The results of the three-year study were published last year.

John and Margaret have recently supported UK Transplant’s “Leave more than memories” campaign (see page 3).

John explained: “David was a keen motorcyclist and he died on the road, the innocent party in an accident. Knowing that our son helped the lives of four other people was, and always will be, a great support for my wife and me. “This campaign is a major chance for drivers to really do something about the chronic shortage of organs for transplants by registering their wishes on the donor register.”

What John and Margaret see as their biggest achievement in 20 years is to have shaped BODY into the caring and quietly influential organisation it is today. “In 1983 we knew nothing about organ transplantation and were amazed to find that no support organisation of its type existed,” said John. “We’re not a public profile organisation, that’s not what we set out to be. We give a confidential service and lobby quietly.”

The focus of BODY’s 20th anniversary is their annual convention, which takes place in Cambridgeshire on 18-19 September. This event will bring around 200 donor families, recipients and health professionals together to share experiences.

For more information about BODY and for details of publications and other resources see the website: http://users.argonet.co.uk/body/
APPOINTMENT WITH...

Mr Peter J McDonnell

Peter McDonnell is a Consultant Ophthalmic Surgeon at the Birmingham and Midland Eye Centre, City Hospital, Birmingham and Chairman of UK Transplant’s Ocular Tissue Advisory Group. His special interests include corneal transplant surgery, corneal and external eye diseases and complex cataract surgery.

Peter received his medical training at the University of Oxford and then St Thomas’ Hospital in London and qualified in 1978. He had his first experience of ophthalmology as a Senior House Officer and then went on to train in ophthalmology at St Thomas’ Hospital in London and Moorfields Eye Hospital in London. Peter was appointed as Consultant Ophthalmic Surgeon in 1990.

Q What prompted you to become involved in ophthalmology?
A When trying to decide what specialty to follow I found that I liked both medicine and surgery. I remembered the enthusiastic teaching at the Eye Department, St Thomas’ Hospital, and this encouraged me to go into ophthalmology as this specialty provides an excellent combination of very challenging surgery and also has elements of the more medical side of the management and treatment of eye conditions.

Q What else might you have done?
A I might have considered one of the other surgical specialties such as plastic surgery or ear, nose and throat surgery.

Q What aspect of your current role gives you most satisfaction?
A Although as I move through my career I am inevitably involved in more management work, it is still involvement with patients that gives me the most job satisfaction, in particular the result of a successful operation in bringing about a big improvement in vision and an improved quality of life for the individual patient. However, I do also enjoy my involvement with the more administrative side of ophthalmology through my work as Chairman of the Ocular Tissue Advisory Group at UK Transplant and also my work as a Council Member of The Royal College of Ophthalmologists. These posts give me the opportunity to be involved in developing how ophthalmic healthcare is delivered and, hopefully, improving ophthalmic services at a national level.

Q What aspect do you least enjoy?
A Although it is an inevitable part of the job as a consultant, I have to say that I dislike the very high level of the paperwork involved. It is also sometimes frustrating when one’s ability to deliver a high quality ophthalmic service is limited by problems with resources.

Q What one piece of advice would you give to someone new to ophthalmology?
A I would say stick at it. Ophthalmology is a very competitive specialty, probably because a lot of people have realized it is a very good specialty to be involved in as a doctor. It is also helpful to have a mentor and most consultants in ophthalmology are willing to be approached by people at the start of their career to give advice.

Q What has been the greatest success so far in your career?
A As a doctor I tend to think of success or failure in terms of how individual patients do after the treatment I have given them. In terms of individual patients, the greatest success I have had in recent years has been a very good result in a lady patient in her 30s who underwent corneal transplant surgery in her only eye. This improved her vision from only being able to see vague shadows to being able to see about two thirds of the way down the vision chart. She tells me that for the first time in her life she could quite clearly see her children and also for the first time in her life she could see the stars in the night sky. It is the effect on individual patients like this that means the most to me.

Q What has been the most radical change since you have been involved with the transplant community?
A When I first started performing corneal transplant surgery in the early 1980s at St Thomas’ Hospital, London, there were only corneas available locally from the hospital where the surgery was being performed. The patient therefore had to be admitted and told that we would not know until the end of the afternoon operating list whether we would have successfully obtained suitable corneal graft material that day. Quite often the surgery had to be postponed as no material was available. With the start of the Eye Bank at Bristol this revolutionized the planning and delivery of corneal transplant surgery as it became possible to book patients in for a given date for corneal transplant surgery knowing that the corneas would be available as the Eye Bank is able to store corneas for up to 30 days.
Patients' Forum

Patients' Forum met on 10 October 2003

- Consideration was given to advertising to gain representation at the Patients' Forum from minority ethnic groups.
- Members noted that a pilot Patient Consent Scheme Working Group had been set up.
- Members expressed their disappointment at the decision to discontinue the “Vote for Life” campaign due to legal restrictions.
- Recent activity to increase donor numbers was reported and members recounted their own involvement in local awareness campaigns.

Pancreas Task Force

PTF met on 31 October 2003

- The Department of Health has agreed to fund a national pancreas service for England, based on the seven centres currently performing the procedure. In Scotland the Scottish Executive already funds the service centrally. Residents of Wales and Northern Ireland will be funded through separate arrangements.
- A national scheme for pancreas allocation began in August 2003 and since that time there have been five simultaneous pancreas/kidney and three pancreas only transplants.
- Pancreata not suitable for whole organ transplantation will be offered for islet transplantation via a nominated on-call co-ordinator at Oxford.
- The current areas of responsibility for retrieval of pancreata would continue for a further 12–18 months to enable a review to be undertaken of feasible zones. These arrangements are such that each pancreas transplant centre covers its own renal retrieval area/alliance. Where there is no local retrieval centre then the centre accepting the transplant will retrieve.
- An analysis of activity since January 2000 had indicated that sensitised patients were waiting longer for a transplant than those not sensitised. The feasibility of a preferential sharing scheme for these patients was felt to be impractical given the small number of organs currently retrieved. It was agreed that sensitised patients should be made aware of this situation in order for them to be considered for a kidney only transplant.

Liver Advisory Group

LAG met on 5 November 2003

- Members considered the report on liver transplantation in the UK for Group 2 patients. It was felt that the term “medically unsuitable for transplant” was not appropriate and more suitable terminology should be used.
- It was agreed that the current registration criteria for super-urgent liver transplantation required updating in the light of current practice and following an analysis of the patients registered under the existing criteria.
- The requirements of the Freedom of Information legislation in relation to members’ contributions to the work of the advisory groups were noted.

Kidney Pancreas Advisory Group

KPAG met on 26 November 2003

- The national data set for renal data was agreed by KPAG. This would now be discussed by UKT, NHS Information Authority (NHSA) and the Renal Registry to produce a national renal data set by April 2005.
- The annual review of the current Kidney Allocation Scheme was presented. The scheme continues to produce the results for which it was established. In particular the level of HLA matching achieved in both adult and paediatric kidney transplant recipients in the UK continues to improve.
- A pilot scheme on the reallocation of blood group A2 kidneys to blood group B patients is to be set up by the North Thames alliance in order to improve the current low transplant rates in Group B recipients.
- The most appropriate way of allocating kidneys from non-heartbeating donors was considered and an analysis of factors influencing results is now under way. This subject will also be discussed at the Renal Transplant Services meeting in March 2004.
- Current inequities in the kidney allocation system are to be considered by a new working group. This group would be reporting back to KPAG in December 2004 with recommendations for possible changes to the National Kidney Allocation Scheme.

Audit, Analysis and Research Group

In October 2003 the UKT Board agreed changes to the Audit, Analysis and Research Group. This group was set up in 2001 as part of a wide-ranging review of UKT’s advisory group structure. Its principal role was to provide an improved process for linking clinicians and statisticians. With the appointment of the Director of Statistics and Audit it was agreed that the role of AARG should be reviewed.

The resulting proposal was that each organ specific advisory group would have their own formally constituted audit sub-committee. These groups will include appropriate clinicians, any necessary external contacts and nominated UKT statisticians: they will meet at least twice yearly before the advisory group meetings. The main AARG will continue to meet on an ad hoc basis when necessary and be chaired by UKT’s Director of Statistics and Audit. These changes will enable statisticians within UKT and the advisory groups to remain focussed on issues of priority.
Legal advice produces practical guidance for co-ordinators’ use

Recently some transplant co-ordinators have found themselves in the position of being asked whether a deceased partner can donate sperm. As a result UKT has sought legal advice.

The law is such that it would actually be possible to retrieve sperm (or eggs) but not possible to store sperm (or eggs) without the written consent of the donor. Although it is not impossible for such a situation to arise it is highly unlikely, as the donor would have had to have given written consent before death.

The removal of gametes from a deceased person is governed by the Human Tissue Act 1961. However, once removed, the storage and use of gametes falls within the regulatory remit of the Human Fertilisation and Embryology Authority (HFEA). The storage of gametes is illegal in the absence of prior written “effective consent” from the donor to storage.

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Around 700 families and friends of organ donors attended a **commemorative service at Manchester Cathedral** in January. The service, organised by transplant co-ordinators, was in remembrance of 120 organ donors, most of whom died since 1998. The idea for the service came from the donor family group based in the north west, and some of the group helped to arrange the event.

“The service was a celebration of the lives of these people,” explained transplant co-ordinator Dawn Lee. “It was extremely moving, but a very positive occasion. Cards and emails we’ve had from the families who attended have said how much it’s helped them.”

Looking for new areas to promote organ donation registration Mike Hope, regional transplant co-ordinator, hit upon the idea of **running a stand at Sheffield University’s Refreshers Fair** this February.

The fair was the second of two organised annually by Student Connection, the University of Sheffield’s Union of Students. Around 8,000 students and staff came through the doors, keeping Mike and the rest of the Northern General Hospital team very busy. They signed up over 200 students to the ODR on the spot and gave away an additional 1,000 registration forms.

Mike said: “Once you get talking, young people are really receptive to the idea of organ donation. It’s something which many of the students I spoke to had never thought about before.”

Transplant co-ordinators and transplant nurses from Plymouth, Treliske and Bristol in the South West Donor Co-ordinating Team have booked the Donor Bus and are **taking part in the Devon County Show** in May. The show attracts over 80,000 people each year over three days.

The team has also negotiated three months of free advertising on ten Plymouth buses in the run up to National Transplant Week (see page 9).

A **study day in the North Trent NHS region** was held last October at Sheffield’s Northern General Hospital. The day, organised by transplant co-ordinator Sue Siddall and donor liaison nurse Christian Brailsford, also commemorated Leah Giles who died in 1997 in a road accident.

Key to the day was the involvement of Leah’s parents who were told, incorrectly at the time of her death, that Leah could not become an organ donor because she was killed instantly. Her parents underlined the need for improved information and communication, and highlighted the importance of support from transplant co-ordination teams.

“What made the day particularly successful was the variety of people it attracted,” explained Christian. “They included lecturers and consultants as well as nursing staff from different areas of the hospital. We were pleased to have family liaison officers from the police force and as a result they’ve actually changed their policy on asking families about tissue donation.”