

17
January

Annual Conference & AGM

Saturday 17th January 2015

**DoubleTree by Hilton London West End,
Southampton Row, London WC1B 4BH**

Coffee/tea and biscuits from 9.30am.

10.00am Welcome and introduction

AGM: Chair's report; Treasurer's report; Confirmation of Trustees

11.00am **Speakers:**

Lisa Burnapp: Who gets your kidney?

Hannah Maple: An update on research around altruistic donation

David Lee: YouGov survey results three years on

12.30pm Lunch

1.30pm Group photocall (for those wishing to take part)

1.45pm Jan Shorrocks: A year in the media and lessons learned

2.00pm Panel discussion: How do we keep the momentum going?
facilitated by David Lee

3.00pm Richard Pitman: Persuading others to jump the fence

3.30pm Summary & Close

Lisa Burnapp is Lead Nurse, Living Donation, Organ Donation and Transplantation, NHS Blood and Transplant & Consultant Nurse, Living Donor Kidney Transplantation, Guy's & St. Thomas' NHS FT
David Lee is an Economic Consultant with CH2M Hill and recently joined the Steering Committee
Hannah Maple (Guy's Hospital) previously a surgeon, is now studying for a Phd in Psychology and writing a thesis on the psychology of living donation
Richard Pitman is a retired jump jockey, author and journalist
Jan Shorrocks is PR Officer for Give a Kidney

This is a FREE event. To book, email suzannadendulk@googlemail.com
or book through www.eventbrite.co.uk

Give a Kidney would like to wish all its members and supporters a very happy Christmas and New Year



Get campaigning!

With a general election on the horizon, now is a good time to lobby politicians and provide them with a topical issue for a soapbox: the need for more donors to come forward to reduce the waiting list for transplantation and thereby save the NHS millions of pounds over the next few years - vital funds which could be put to better use elsewhere in the NHS. The Budget and the NHS are both subjects high on the agenda for all politicians - so this is an opportune time for exposure of Give a Kidney and its own agenda.

Brains of kidney donors seem built for generosity

As if giving a perfectly good kidney to a total stranger wasn't enough of a distinction, it turns out that extreme altruists have bigger brains and are better than the rest of us at reading signs of distress in facial expressions.

That's what neuroscientists at Georgetown University, Washington DC, found when they rounded up 39 altruistic/non-specified donors and scanned their brains, according to a recent study. Psychologist Abigail Marsh thought it would be tough to round up a significant number of people who had donated kidneys to strangers. She was pleasantly surprised. They were easy to

find because many now advocate for organ donation. And they really want to do good things.

"What was amazing about them - and I guess it shouldn't have surprised me, in retrospect - was how incredibly easy they were to work with," Marsh said. "They



could not have been more delightful study participants."

The participants stayed motionless during multiple brain scans, patiently looked at lots of facial expressions flashed at them for milliseconds, and didn't take umbrage to answering 154 questions usually posed to those suspected of being psychopaths. And when the results came in, many thought the data proved just how much organ donation improves humans, Marsh said.

Researchers, however, believe it's the other way around: Extreme altruists appear to be built for better empathy.

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Research: please get involved

Give a Kidney is currently involved in two research projects which have recently received approval. It is hoped that many members will take the opportunity to get involved and contribute in the course of the projects.

The larger of these projects is a five year study headed by Nizam Mamode, a consultant transplant surgeon from Guy's and St Thomas's Hospitals, and involving Paul Gibbs, consultant transplant surgeon from Portsmouth (Give a Kidney Trustee), Lisa Burnapp from NHSBT and the psychology departments from Kings College London, University of Plymouth and the Royal Devon and Exeter NHS. David Hemmings and Jan Shorrocks, altruistic donors and members of the Give a Kidney steering committee are also on the project team representing the patient element.

The aims of the research project will be to assess the implementation of the 'unspecified donor' programme to determine whether there are barriers to donation arising from different attitudes towards donation or economic problems.

1. Is there variation in transplant professionals' practice and attitudes, which is preventing some unspecified donations?
2. Are psychosocial and physical outcomes after unspecified donation equivalent to those after specified donation?
3. What is the economic benefit from unspecified donation?

Inspiring others by spreading the word

Kathleen Bond was the £50 winner for Reader's Letters, Saga Magazine, October 2014. She writes:

Donor's delight

In July 2013, your cover story was on 'altruistic non-directed kidney donors', with six personal case histories as to what motivates them. Reading this certainly had a very positive effect on me: so much so that I have now done the same thing. It has been an incredible journey. I am in total awe of the skills, dedication, care and support of the team at the Oxford Transplant Centre at Churchill Hospital, and they well deserve a mention. I shall never know who my recipient is: it's enough for me that I have had the chance to give someone back their life. I have had the best health check ever after a series of very stringent tests and, at 70 years old, feel very humble to have been able to do this, all because of reading your article.

Kathleen Bond

Did you know that you can donate to us by getting rid of your old car?

Giveacar (a not-for-profit social enterprise) will collect the vehicle for FREE, scrap or auction it, and the money raised is sent to your charity of choice.



A scrap car donation could raise about £100 for Give a Kidney (depending on the price of metal) and an auction could generate much, much more in terms of helping someone with kidney failure. For the service Giveacar retains 25%+VAT of the proceeds, but that's still a very healthy amount for the Charity. So if you have an old car you no longer need, why not put it to good use?

Simply call **0207 736 4242** or check out www.giveacar.co.uk to arrange your free collection.

Giveacar take cars of any age or value and will collect from anywhere in the UK!

✓ Free collection ✓ Any car ✓ Countrywide



The research project involves three inter-linked studies delivered over five years:

Transplant Professionals study

Interviews will be undertaken with 60 transplant professionals (surgeons, physicians, psychologists and co-ordinators) from both high and low volume unspecified donor centres. The interviews will identify the attitudes and experiences relating to the donor process, followed by a questionnaire survey of all transplant professionals in the UK involved in unspecified donation. This will be undertaken to ascertain barriers or facilitators to donation.

Donor study

Individuals presenting to transplant teams in the UK for unspecified donation over a three year period will be recruited. Based on historic trends we expect to recruit about 780 individuals, of which circa 224 will proceed to donation. Follow-up data will be collected before and after donation, for those that proceed to donation. Variation in donation rates between

centres will be examined. Additionally, a control group of 200 specified kidney donors will be recruited and similar data will be collected. Some 45 unspecified donors who either donated or who withdrew will be interviewed.

Economic study

Using scientific modelling, the longer-term cost-effectiveness of unspecified donation will be examined.

The output of the project will be guidelines, for use by both transplant teams and commissioners of transplant services. The project has been approved and funded by the NHS National Institute for Health Research.

The second, smaller project is being lead by a long time supporter of Give a Kidney, Dr. Alexis Clarke - a clinical psychologist from the University of Plymouth. It will be investigating the barriers and enablers to altruistic kidney donation in the family and friends of donors. This study aims to improve the understanding of the needs of donors and their families and friends and why some people drop out of the process. The aim is to produce recommendations for the health services involved and literature for family and friends which will address any concerns identified by the research.

This project has been funded by the British Kidney Patient Association and the British Renal Society.

Surgeons carry out first European keyhole kidney transplant

Whilst surgeons have *retrieved* kidneys from donors using keyhole surgery for a number of years, the technique has not been used to transplant kidneys *into* patients until recently

Surgeons at the Royal Liverpool Hospital have carried out a kidney transplant using keyhole surgery, a technique that offers patients the chance of a much faster recovery after the operation. It is the first time the procedure has been performed in Europe.

Instead of making a sizeable incision to perform the transplant, the team at the Royal Liverpool used keyhole surgery to implant the donor kidney through an incision of just 6cm (2in) which is a lot less invasive for the patient and heals more quickly.

The technique was developed by Professor Pranjal Modi at the Institute of Kidney Diseases & Research Centre in Ahmedabad, India. He is the only surgeon in the world who has used the method. Consultant transplant surgeon Sanjay



Pranjal Modi, MS, DNB

Mehra at the Royal Liverpool Hospital arranged for Prof. Modi to spend a week at the hospital, where he carried out the operation three times. Sanjay Mehra, who assisted with the operation, believes there are significant benefits:

“There is a huge difference in the size of the scar, which has a cosmetic benefit. But also in the long scar there is muscle cutting, which can give problems in the long term.”

The recipient was Brian Blanchfield, a 51 year old company director from New Brighton who had spent years living with a failing kidney before his sister Pam donated one of hers. He was up and about just four days after the operation.

He told the BBC: “I’m feeling good. They said I’d be the first one to do it, and the interesting thing was they asked me where I wanted the kidney to go. So they

went through my appendix scar, as there was already a cut line there.”

This is not a technique that will be used in every kidney transplant. It is most suitable for those patients who are very overweight, where major abdominal surgery carries greater risk. But it shows how keyhole surgery is now providing new options for surgeons in even the most complicated operations.

Taken from an article by Dominic Hughes Health correspondent, BBC News, 9 October 2014



European Organ Donation Congress in Budapest



The event was a fascinating insight into the amazing world of organ transplantation. It drew on expertise from across the world and involved lectures and presentations of research

as well as discussion of contemporary issues around transplantation.

There were delegates from across Europe and beyond, mostly medical or research staff. Much of the information was aimed at them and I now know more than I thought I would ever need to about the ins and outs (no pun intended) of transplanted organs, the latest research, thinking and aspirations!

There were sessions specifically about living donation which were challenging and fascinating. Discussions (sometimes heated ones) around particular case-studies gave me a much greater insight into the work of the co-ordinators and the differences in attitudes across the medical profession and in other countries. It was clear that the UK is a world leader in non-directed donation.

It was also very clear how seriously donor safety and protection is taken by all involved. I was pleased to be able to offer a donor perspective and hopefully challenge some of the more cautious attitudes by sharing our experiences.

Through the networking opportunities it was useful to discuss our work directly with UK Living Donor Co-ordinators. I was also able to make valuable links with contacts from other countries, particularly The Netherlands who are currently setting up a non-directed donor advocates group, similar to Give a Kidney. I shared some of our experience, and have offered to speak to any donors involved if required.

There were some informal discussions about terminology. As well as ‘non-directed’, the other term that appears to be commonly used is ‘unspecified donors’. There was a feeling that ‘altruistic’ is not a term that most people feel comfortable with, as surely every donor (directed or otherwise) fits this term.

There was a strong recognition in some presentations that unspecified donations are incredibly valuable, particularly with the increase of chain donations, but there are still very few countries currently

allowing it. Hopefully more may consider it in future.

Overall, the conference was an inspiring insight into the complex and marvellous work the medical staff across the world carry out to save or improve people’s lives through transplantation. I was delighted to be there to be able to represent non-directed donation from a donor perspective.

Dialysis Commissioning: National Kidney Foundation’s call to action

Many of you will be aware of the proposals from NHS England to transfer responsibility for the commissioning of the dialysis services from NHS England to Clinical Commissioning Groups (CCG’s) from April 2015. The National Kidney Foundation (NKF) has published a briefing paper and is asking their members - and anyone else who’d like to get involved - to read it and complete a questionnaire and/or write to their MP. If you are interested in taking action, visit the NKF website at www.kidney.org and click on the links.

'Brains of kidney donors seem built for generosity' contd.

Compared with others, the 39 donors had slightly bigger brains, by about 9%. That's not what interested researchers, per se. It was the marked difference in volume of the right side of the amygdala - a brain region that processes emotional stimuli such as fear or distress.

Marsh and her colleagues wanted to measure whether that region also was more active in response to facial expressions. The difference was significant, but not as extreme as their rare acts of altruism might suggest, they found.

"They weren't so far from the average of the controls," Marsh said. "They're merely at the high end of the capacity for compassion and emotional sensitivity, which is sort of encouraging. It suggests that maybe there are many more people out there who might be interested in donating to a stranger than who actually donate."

The researchers believe the data

supports the hypothesis that our ability to care about the plight of others falls within a spectrum, with psychopaths anchoring one end and extreme altruists the other.

While there are many ethical and moral explanations for altruism, scientists looking for a biological one have been stumped. Why would someone behave in a way that could diminish their chances of survival, with no tangible benefit to them? Some suspect altruists merely expect a similar favour that might help them later, or are investing in the survival of DNA shared by kin or a social group. Neither theory has drawn a consensus.

Marsh leans toward an alternative hypothesis posed by others. Natural selection would favour those who can accurately read the meaning of their infant's facial expressions. After all, the size of the amygdala correlates with social complexity among animals, she noted.

"Because we are mammals that give birth to these very helpless young, we're predisposed to respond to anything that reminds us of a vulnerable, helpless infant," she said.

Although it offers a hint at a biological predisposition to higher empathy, the study also suggests that many factors probably have to coincide to produce behaviour as rare as donating a kidney to a stranger. The study found no significant difference between the control group and extreme altruists across factors such as income, education, sex and race. But future studies will examine other environmental issues, such as the donors' sense of well-being, Marsh said.

The easy part, researchers now know, will be getting donors to participate.

Taken from an article by Geoffrey Mohan in LA Times, September 16, 2014

First steps towards becoming an altruistic kidney donor

If you are considering donating a kidney, or would like to talk to someone for further information, contact the Living Donor Co-ordinator Nursing Team at your closest kidney transplant centre (locate them on www.nhsbt.nhs.uk) or get in touch with us at giveakidney@gmail.com and visit www.giveakidney.org

Lifesaver event – Oxford Saturday 29 November 2014

Together with Richard Pitman and Jan Shorrock, I was invited to speak at the Lifesaver event in Oxford organised by Dr. Mazed Mohammed and Dr. Ruchir Mashar to raise awareness of organ donation. We had been asked to talk about our experiences as altruistic kidney donors.

The speakers included a kidney transplant recipient from a deceased donor, a husband and wife where the wife had donated a kidney to her husband and a young man who had watched his father die for want of a liver transplant; all very poignant and emotional stories. We then heard from a specialist nurse for organ donation, who told us about how she approaches the grieving relatives of a terminally ill patient to discuss the possibility of deceased organ donation.

Other organisations represented were LiveLifeGiveLife, Kidney Research UK and Oxford Marrow, the Oxford students branch of the Terrence Higgins Trust; as ever it is always a delight and very useful to talk to kindred spirits.

We gave the final contribution; I spoke about the formation of Give a Kidney and

what we had achieved to date, about my personal experience as a donor and the impact of a letter from my recipient. Richard recounted what had motivated his donation and true to form included the odd amusing anecdote from his experiences which brought a very welcome lighter note to the proceedings. Jan concluded with how she had been inspired to look into donation after listening to altruistic donor Di Franks on the radio, going on to explain her role as Press Officer for Give a Kidney and the vital importance of working with the media to help raise awareness of organ donation.

Initially we had been told that perhaps 200 people might attend, but in reality there were only about 30. Importantly, at least half of those present were junior doctors working in hospitals and research. This just goes to show how important the work of Give a Kidney is, we must continue to raise awareness of altruistic kidney donation in any way that we can and keep at it - it was never going to be easy!

David Hemmings, Trustee, Give a Kidney

Diality

From 'I Knew the Bride' a collection of work by poet and dialysis patient **Hugo Williams**

*The shock of remembering,
having forgotten for a second,
that this isn't a cure,
but a kind of false health,
like a drug addiction.*

*It performs the trick
of sieving you clean of muck
for a day or two
by means of a transparent tube
full of pinkish sand.*

*Your kidneys like the idea
of not having to
work for a living
and gradually shut down.
Then you stop peeing.*

*Dialysis is bad for you.
It takes you by the hand,
but it doesn't lead you anywhere.
The shock of remembering,
having forgotten for a second.*

Contact us

Give a Kidney - one's enough,
PO Box 65885, London N7 1BR
giveakidney@gmail.com
www.giveakidney.org