

Direct action for kidneys!

Last November saw the launch of the charity - *Give a Kidney - one's enough*. The charity originated when retired medical consultant Chris Burns-Cox contacted Annabel Ferriman (Senior News Editor at the BMJ and a kidney donor), and together they developed a steering group and registered the charity. Its aims are to raise awareness, and to provide help and support for people who would like to donate a kidney - specifically those who donate to a stranger (known as 'altruistic' donors) rather than a member of a family or friend.

The website (www.giveakidney.org) is entirely staffed by volunteers and enables 'would be' donors to have contact with 'have been' donors, and familiarise themselves with all the issues surrounding kidney donation - medical and otherwise.

The Launch

The appeal for altruistic donors was launched by Channel 4 News presenter Jon Snow, who said: "Nobody needs telling that the crisis in kidney donation is acute." Since 2007, 88 people have donated a kidney to a stranger. Patients typically live 10 to 15 years longer with a kidney transplant than if they were kept on dialysis. The long-term risk of dying from donating a kidney is no greater than for anyone of a similar age who has not had a kidney removed.



Speakers at the launch: Chris Boustead, Jenny Dale, Jon Snow, Annabel Ferriman, Paul Gibbs, Nicholas Evans



One of our patrons, writer Nicholas Evans lost the function of his kidneys after eating poisonous mushrooms, but has had a new lease of life thanks to his daughter who donated her kidney to him last year.

Membership appeal at GAKOE's first conference

The *Give a Kidney - one's enough* charity's first conference was held at BMA House on 4th February 2012. The Chair and one of the founder members of the charity, Annabel Ferriman, welcomed everyone, reminding them that without their support, the charity would not be possible. Present on the day was Nicholas Crace who at 83 will be the eldest altruistic donor to date.

An enthusiastic appeal for members followed, being a vital way of developing supporters, strengthening the charity and helping key members steer its direction.

The first speaker of the day was John Scoble, Consultant Nephrologist at Guy's Hospital and also a kidney donor who has been raising awareness of altruistic donation for a long time. As a nephrologist (kidney transplant physician) he found it an interesting experience to be faced with the emotional side of the kidney transplant process – yet rewarding.

Two speakers from successful charities gave their perspective on setting up a

SPREADING THE WORD on Community Awareness Day in Normanton, West Yorkshire

PC John Bennett of the West Yorkshire Metropolitan Police invited Sue Jepson, a *Give a Kidney - one's enough* (GAKOE) donor panel member, along to their community awareness day in Normanton town centre. A police mobile portacabin had been set up in the town precinct, along with a portable tent and tables.

The aim of the day was to help raise the profile of the local constabulary. They were giving out free badges, sweets, stamping bikes as well as answering queries from the local population. Sue had been asked to come along after emailing a GAKOE poster to them accompanied by a request to help publicise the GAKOE

charity. They happily printed the poster and invited Sue to attend their community day.

She was given a table and notice board space to display information on *Give A Kidney – One's Enough*, NHS Blood and Transplant Services and the Organ Donor Register. She spoke to local people about the need for additional help to reduce the transplant waiting list.

She ordered free pens and pencils from the NHSBT website and created her own GAKOE t-shirt and keyrings, handing them out to anyone taking an interest. More than 200 people took leaflets and spoke to Sue



about the charity. Local shops displayed the GAKOE poster and took information leaflets to pass onto customers. Sue's decided that next time she's going to do it with a bucket or collection box, as some people asked if there was a donation box! **If you too would like to help publicise altruistic kidney donation, get in touch!**

Fit to go!

Giving a kidney away doesn't mean you are less fit and healthy.

Jenny Dale, a mother-of-two from Bournemouth last year took part in a charity cycle ride to Paris 12 weeks after donating a kidney to a stranger. With her sister, she cycled over 700 miles from London to Paris in aid of Transplant Links – a UK-based charity for people in the developing world with kidney disease. This year, Jenny is planning to cycle London to Brighton overnight, in the dark, in fancy dress to raise more money for the cause.

Jenny, a Dorset Police scenes-of-crime officer, said she decided to volunteer to donate a kidney after reading about the shortage of transplant organs on the BBC News website. "I knew two twin brothers who needed liver transplants," she said, "and just seeing the impact on the family of being on the waiting list really hit home. I thought: 'I can't give a liver, but I can give a kidney. I can actually change one person's life' – and it's not often we get the opportunity to change someone's life."

Jenny said the moment she was told her kidney had been transplanted into a young man was "one of the most amazing things I've heard in my life".

Membership appeal continued...

charity: Anna Bentinck who helped start up Antenatal Results and Choices (ARC), a service for parents who are told during their pregnancy that their baby has an abnormality and Isabel Walker, from Action on Pre-Eclampsia (APEC) – a founder member and co-author on the subject of pre-eclampsia, a complication of pregnancy.

Interactive sessions at the conference got everyone eagerly discussing ways in which the charity could develop, setting goals, raising funds and awareness of the desperate need for altruistic donors to come forward.

Alexis Clarke who recently gained a PhD in Psychology at Plymouth University, outlined the results of her work - the first piece of qualitative research on altruistic donation in the world. Her aim was to understand altruistic donation from a psychological but also social perspective. Alexis had interviewed 14 people, and found that generally people like feeling connected to others; donation seemed to ripple from the positive impact. However, it was common that people felt they had to renegotiate their sanity with others! Alexis has secured funding to spend on further research on the subject but involving the wider community.

An appeal to the Black, Asian and Minority Ethnic community for possible donors to come forward: 3% of those on the donor register are BME, yet 26% of those on the waiting list are BME.
Let's change those statistics!



What my new kidney means to me...

by Chris Boustead



It is difficult to put into words the difference receiving a kidney has made to my life. I suffered acute kidney failure in 2007 and was facing a long time on dialysis while waiting for a transplant. Three members of my family came forward to donate a kidney to me. Unfortunately it was not to be and all three were unable to donate. I guess at that point it hit home to me. Before that I always thought I would not be on dialysis for too long. I tried my best to live a normal life and was able to work full-time but that took most of my strength and energy.

Several years passed then out of the blue I had a telephone call from the hospital – they had a "very special kidney" for me. It was from an altruistic

Saving lives and saving the NHS some cash.

There are now almost 100 altruistic donors in the UK. Read the stories of some of them, pictured here, on our website: www.giveakidney.org

Keeping someone on a dialysis machine costs about £29,000 a year, or £290,000 over 10 years.

The cost of a kidney transplant over 10 years, by contrast, comes to only £102,000, which includes the cost of the operation, the cost of follow-up appointments and of drugs that the patient has to take to stop the body rejecting the organ. So the saving over a 10 year period is almost £200,000 per person/recipient. That money could go to fund other things within the NHS.



donor. The transplant went very well and I was out of hospital in 6 days. I felt great almost immediately. Life was a joy again!

Towards the end of 2011 I met my kidney donor. It was a very special moment for me just to be able to thank her for such a wonderful gift and explain what a difference she has made to my life.

We need members

If Chris's story here has inspired you, please sign up and become a member of Give a Kidney - one's enough. We would like all our current supporters to become members, and to spread the word to others so we can build capacity and help us put our aims into practice. There is no subscription fee. Please email Sue Birbeck on giveakidney@gmail.com and she will enrol you.

WOULD YOU CONSIDER DONATING ONE OF YOUR KIDNEYS?

6,500 people are on the waiting list for a kidney transplant. Each year 4,000 people who could benefit from a transplant are not getting one, and 300 people die each year while waiting.

If you'd like to talk to someone about donating one of your kidneys to someone in need, contact the Living Donor Co-ordinator in your closest Kidney Transplant centre - listed below. Or if you'd like some initial general information and to read some personal stories from donors and recipients, visit www.giveakidney.org

Kidney (Renal) Transplant Units

Belfast	City Hospital	www.belfasttrust.hscni.net
Birmingham	Queen Elizabeth Hospital	www.uhb.nhs.uk
Bristol	Southmead Hospital	www.nbt.nhs.uk
Cambridge	Addenbrooke's Hospital	www.addenbrookes.org.uk
Cardiff	University Hospital of Wales	www.cardiffandvale.wales.nhs.uk
Coventry	University Hospital	www.uhcw.nhs.uk
Dublin	Beaumont Hospital	www.beaumont.ie
Edinburgh	Royal Infirmary	www.nhslothian.scot.nhs.uk
Glasgow	Western Infirmary	www.nhsggc.org.uk
Leeds	St James's University Hospital	www.leedsth.nhs.uk
Leicester	General Hospital	www.uhl-tr.nhs.uk
Liverpool	Royal Liverpool University Hospital	www.rlbuht.nhs.uk
London	Guy's Hospital	www.guysandstthomas.nhs.uk
London	St George's Hospital	www.stgeorges.nhs.uk
London	The Royal Free Hospital	www.royalfree.nhs.uk
London	The Royal London Hospital	www.bartsandthelondon.nhs.uk
London	West London Renal and Transplant Centre	www.imperial.nhs.uk
Manchester	Royal Infirmary	www.cmmc.nhs.uk
Newcastle	Freeman Hospital	www.newcastle-hospitals.org.uk
Nottingham	City Hospital	www.nuh.nhs.uk
Oxford	Churchill Hospital	www.oxfordradcliffe.nhs.uk
Plymouth	Derriford Hospital	www.plymouthhospitals.nhs.uk
Portsmouth	Queen Alexandra Hospital	www.porthosp.nhs.uk
Sheffield	Northern General Hospital	www.sth.nhs.uk



World Kidney Day

8 March 2012

World Kidney day is a joint initiative of the International Society of Nephrology (ISN) and the International Federation of Kidney Foundations (IFKF).

The mission of World Kidney Day is to raise awareness of the importance of our kidneys to our overall health and to reduce the frequency and impact of kidney disease and its associated health problems worldwide.

If you are doing something to mark World Kidney Day, let us know so we can feature your event/activity in the next GAKOE newsletter!

Meet Sue Birbeck



Give a Kidney - one's enough has a new temporary administrator: Sue Birbeck agreed to step into the role until a part time administrator is appointed.

If you know anyone who would like to support the Give a Kidney charity, donate or raise funds, become a member or help in any other way, please let Sue know.
Email giveakidney@gmail.com

Losing an organ but gaining a smile...

A year in the life of one donor (dates and names have been altered)

12th January: Went round to Sue's last night for a meal. I asked how she was going to spend her birthday and she said she'd be in hospital giving away a kidney! Wow! I didn't know it was possible. I knew in a flash that's what I want to do too ... a chance for me to do something particular and personal to help someone, it's like I've been working up to this for years without knowing it.. I made an appointment today to go and find out more from Sarah Stacey, the Kidney Transplant Co-ordinator at Derriford Hospital.

14th January: Saw Sarah Stacey today. She's a bubbly person and I liked her immediately. But more importantly she was very thorough and we spent a long time going over what would be involved. I felt full of bounce as I left - though sobering to see some of the people in the renal unit going in for dialysis. They just looked so ill. If I had any doubts – which I don't – this would definitely dispel them.

22nd February: Spoke to Hettie today. Feel a bit gutted because she doesn't understand my motives – I think she thinks I'm

being selfish and she can't understand why I might want to deliberately harm myself for someone I don't know – but for me it doesn't make any difference whether I know them or not, a life is a life and I can do something about one that's gone wrong. Her reaction doesn't affect my resolve, it just makes me sad.

14th August: I think I need a season ticket for Derriford car park! There have been so many different tests, needle pricking, scans, etc. and a meeting with a clinical psychologist who had to assess my motives and mental health. Everyone has made it so clear I could pull out at any point. I've never wavered from my intention but it still feels good that the safety net is there.

10th October: SO excited!! Sarah emailed me today to say they've found a match for me – someone with the right blood and tissue type, genetic makeup etc. I know it's a woman and where she's from but I'm not told anything else and that's a good thing, I don't want to personalised it as it's bad enough knowing that things just might not work out for that person. So we've

negotiated a date for the op. It's really happening then...

4th November: I've got this funny tingling feeling, knowing that when I come back to this house, this bedroom, my body will be less one vital organ and already installed in someone else. Surreal thought.

10th November: Well I'm back. Sitting typing on my laptop as though nothing has changed. If I'm honest though, the recovery process wasn't as speedy as I imagined in the pink of my health beforehand, and it's still a bit painful walking, but other than that I feel terrific!! The two surgeons who did the op both visited a couple of times in the ward and couldn't have been nicer. They told me the recipient's operation had gone smoothly and she was doing fine - that's just the happiest news. I was born on the right side of the track in so many ways, and feel so fortunate that I've been in a position to do something for someone who hasn't been so lucky.



Chain of 30 kidney transplantations sets new US record

extracted from an article by Kevin Sack ([full article: www.nytimes.com/2012/02/19/health/lives-forever-linked-through-kidney-transplant-chain-124.html](http://www.nytimes.com/2012/02/19/health/lives-forever-linked-through-kidney-transplant-chain-124.html))

A new record for chained kidney transplantations has been set in the United States. It involved 30 transplantations across the country between March and December last year, which linked living donors to recipients whom they were unlikely ever to meet.

Chained transplantations start with a single altruistic donor. If this donor's kidney is used to help a recipient who for incompatibility reasons cannot receive one from a willing relation, the chain can continue if that relation remains willing to donate anyway. That kidney goes to the next recipient in the chain, who also has a willing but incompatible relation, prepared once more to reciprocate the gift by donating onwards. Technically such a chain need not end, but people are excluded who have no relation or partner who is willing to keep the chain going.

The 30 strong chain in the US began with altruistic donor Rick Ruzzamenti, 44, of Riverside, California, who decided one day to give a kidney to a needy kidney patient—any needy kidney patient. He

attributed this spur of the moment decision to his Buddhist beliefs and to the recession, which had temporarily dried up his work as an electrical contractor and given him time to spare.

His kidney was flown across the country to Livingston, New Jersey, where it was transplanted into a 66 year old man. His niece had offered him her kidney, but it did not match, so in recognition of Mr Ruzzamenti's gift she gave it anyway, and it was shipped to a hospital in Madison and transplanted into Brooke Kitzman, 29. In reciprocity Ms Kitzman's former partner, David Madosh, 46, donated one of his kidneys, in spite of the fact that he and Ms Kitzman had just had an acrimonious break up.

And so it went on, until the 30 transplant chain terminated with Donald Terry, 47, in Joliet, Illinois, who had nobody in his family willing or able to donate a kidney.

Chained donations, which take place over several months, have not occurred in the UK, but "pooled" donations, which are carried out simultaneously on the same day, have. There is no legal obstacle to

chained donations in the UK, and from the beginning of this year would-be altruistic donors have been able to choose to donate into a pooled scheme rather than to the next suitable patient on the national transplant waiting list.

Lisa Burnapp, lead nurse for living donation at NHS Blood and Transplant, said, "The story of the 30 long chain shows the future potential for what is possible in living donor kidney transplantation. In the UK we've just embarked on introducing altruistic donor chains into our established national living donor kidney sharing schemes, building on the strengths of our existing paired and pooled donation scheme".

Contact us

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