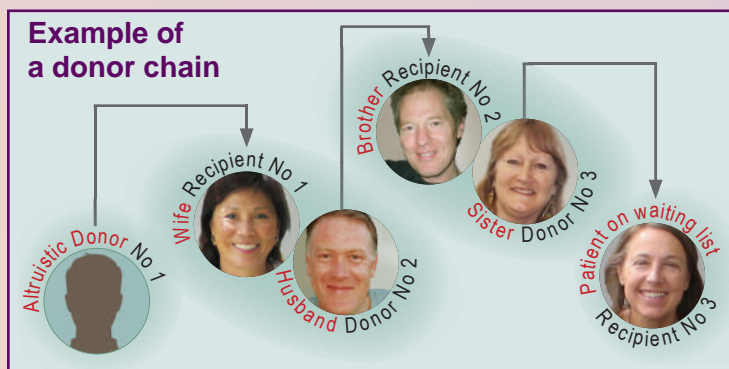


3-for-1: making the most of every donation

With the support of transplant teams all around the UK, NHS Blood and Transplant (NHSBT) has been able to introduce an exciting innovation to the National Living Donor Kidney Sharing Schemes. The change to the scheme was started in April, making it possible for a chain of up to three kidney transplants - instead of one or two - to be triggered from a single altruistic donation. This creates more transplants for the 5,500 patients across the UK who are still waiting for a kidney.

Three years ago, the idea of altruistic donor chains became a reality, encouraged by the number of people choosing to anonymously donate a kidney to someone in need of a transplant. Since then, more than fifty altruistic kidney donors across the UK have created twice as many transplants by opting to join the shared living donor pool. It works by an altruistic donor donating first to a patient with an 'incompatible' donor in the living donor 'paired' pool. The 'paired' donor, in turn, donates to a patient



who is waiting on the national transplant list. By including an additional donor-recipient pair into the chain when pairs are matched together every three months in the 'quarterly matching run', the length of the chain and the number of transplants that can be achieved is increased.

One of the reasons that the change has been made possible is that all the transplant centres around the UK have agreed to try to schedule all the identified transplants within the same two-week period. These designated 'sharing fortnights' mean that all centres are on 'stand by' to plan operations within eight weeks of the quarterly matching runs. This makes a difference because it allows

altruistic donors to plan in advance more easily than they could before: previously, it was difficult to predict when the transplants would actually take place after a chain had been identified and this made it difficult for people to opt into the scheme.

It is early days, but we have already seen a difference: several long (3-

for-1) chains have been identified and more altruistic donors seem willing to consider entering the shared schemes. NHSBT will be monitoring things closely and will work with transplant teams to make improvements where necessary. In the meantime, it is really exciting to be in a position to reward the generosity of altruistic donors by making the very best of every donation that they are prepared to make.

For more info, visit www.giveakidney.org or the living donation pages on the NHSBT website at www.organdonation.nhs.uk

Lisa Burnapp

Lead Nurse, Living Donation, NHSBT

Going Dutch?

Recently, representatives from Give a Kidney met with two people from Erasmus Medical Centre in Rotterdam, which claims to be the largest living kidney donor transplant unit in Europe.

The Dutch team from the Erasmus Medical Centre are keen to start publicly campaigning for non-directed donors as Give a Kidney UK are doing, so it is hoped a further meeting can be set up within the next few months for a more structured discussion. Find out more on their website: www.livingdonation.eu

Chris Burns-Cox

Scotland holds event to raise awareness of altruistic donation

Scotland wins the prize for pro-activity after NHS Scotland, together with the teams from the transplant units based in Edinburgh and Glasgow, held a successful awareness evening about altruistic kidney donation in April. The event brought together donors, recipients and transplant teams along with a panel of medical experts to inform and educate people about altruistic donation and to answer any questions from potential donors.

It was very well attended by many people considering donation and presented a unique opportunity for them to hear stories and ask questions of other donors

(including several Give a Kidney members) and medical professionals. A presentation by a recipient also gave everyone a moving insight into the enormous difference a transplant can make for someone. Donors from the two units were thanked with a presentation of a personalised 'Gift of Life' scroll.

The evening also generated interest from the press, with news stories around donation leading up to the event.

It is hoped that NHSBT with support from Give a Kidney will be able to replicate the event in other regions in the coming year. Watch this space!

A farewell - and welcome to new Trustees for Give a Kidney

Bob Wiggins is an independent corporate and public sector turnaround professional helping organisations to implement radical and fast paced change



to ensure their continued viability. He is a past visiting lecturer in business strategy at the University of Westminster and is a Director of The Institute for Turnaround. Bob donated a kidney in 2013 after some time of research and consideration, and since then, he has supported Give a Kidney in their campaign to raise awareness of non-directed kidney donation.



and previously ITV's World In Action for longer than he cares to remember. Roger is an identical twin and when he donated

Roger Corke is an investigative television journalist who has been making films for programmes like the BBC's Panorama, Channel 4's Dispatches, and

his kidney altruistically to a stranger in September 2013 it was on the basis that, should he ever need a replacement, his genetically-identical brother, Andrew, could provide one. But now Roger knows that, before donating a kidney, you're put through such a gamut of tests to ensure you're healthy that he's very unlikely to need his brother's kidney.

Give a Kidney Trustees are also members of the Steering Committee, so they help shape the charity's direction. Roger and Bob's appointment as Trustees coincides with the departure of **David Hemmings**, who is also a non-directed kidney donor, who resigned after three years in the role. Give a Kidney is immensely grateful to David, who has been an invaluable and diligent member of the Board, and he plans to continue to support the work of the charity in a non-official capacity.



This year, the British Transplant Games will be held in Newcastle-Gateshead, and run from 30 July to 2 August. The Games are expected to attract about 1,500 spectators, and encompass a wide age range - from two to 70 years old. More than 750 competitors will take part in about 17 sports.

This year the organisers are allowing living donors to participate in a few events and march under a 'living donor' banner at the Opening Ceremony. A few altruistic donors are taking part in the swimming events, and there will be a Give a Kidney stall on the Sunday.

Unfortunately the closing date for registration was May 15th, so it's too late to enter this year - but you might want to bear it in mind for the 2016 (Liverpool) or 2017 (North Lanarkshire) Games.

Liverpool medics give hope in Gaza

Give a Kidney's co-founder Chris Burns-Cox gave a talk on living kidney donor transplantation in May at the European hospital in Gaza - his second visit there in two years. Transplant surgeon Abdul Hammad, working with the Liverpool International Transplant Initiative, is carrying out four more transplant operations in Gaza in June.

Kidney transplantation is the best treatment option for patients with end stage renal failure. There are currently 550 patients on dialysis in Gaza. Patients who require kidney transplantation travel abroad to have the procedure performed, but the prohibitive costs mean that, for most patients, this is not an option.

The Liverpool International Transplant Initiative (LITI), through collaboration between the Sir Peter Medawar Transplant Unit at The Royal Liverpool University Hospital and Al Shifa Hospital in Gaza,

aims to establish a kidney transplant program serving the population of Gaza. Having carried out the first ever transplant in the conflict-ridden Gaza strip, LITI's ultimate goal is to establish a local kidney transplant program run by local expertise which will deliver a first class service, with the highest standards of patient care, and LITI are hoping to raise the requisite £500,000.

So far, as well as carrying out 18 transplants, including for six children, LITI has facilitated the training of healthcare

professionals from Gaza at the Royal Liverpool University Hospital. As well as installing an IT system in Al-Shifa Hospital, LITI were successful in advocating for a change in the law, making cadaveric donations legal. A transplant unit is now being built as part of the new surgical unit at Al-Shifa Hospital, and a surgeon has been selected to complete a two year training course at the Royal Liverpool University Hospital.

LITI are currently working to establish an independent transplant authority in Gaza to introduce, regulate and monitor transplant activity, including paving the way for cadaveric donation. Its other main activities include continuing with training, the establishment of procedural and physical infrastructure as well as continuing to visit Gaza to help patients.

To learn more about the project, and to find out how you can help, please visit: www.liverpooliti.com



I lost hope, and thought that maybe I was going to die. But after the operation, I can play with my friends again and go to school and do everything!

Fatima, Age 9

Can you help with this research?

Many people who contact hospitals because they are interested in donating a kidney to a person that they do not know do not end up completing their donation.

The University of Plymouth is undertaking research, led by Clinical Psychologist Dr Alexis Clarke, aiming for a better understanding as to why this is, by focusing on the influence of family and friends. They are looking for altruistic donors or potential kidney donors, and those who have decided not to proceed, to participate in an interview-based study. They would also like to speak with any family members or friends who had a significant influence over their decision to donate or withdraw.

They hope the results will have a direct impact on the assessment and care of future altruistic donors. They would like to

produce written information that targets family members' concerns directly.

The interviews will take around one hour, after which interviewees will be sent a summary to comment upon. Participation is entirely voluntary.

This important project is being funded by the British Renal Society and British Kidney Patients Association and fully supported by Give a Kidney. If you'd like to be involved, please contact Alexis Clarke for more information:

Email: alexis.clarke@plymouth.ac.uk

Tel: 07940 729500, or write to:

Dr Alexis Clarke, Clinical Psychologist
University of Plymouth,
Faculty of Health & Human Sciences,
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Meeting Terry

After initial reservations, Bob Wiggins meets the recipient of his kidney

On 11 April 2015 I woke up filled with extreme apprehension. For the first time I would be meeting Terry, the recipient of my kidney I donated two years earlier.

Remaining anonymous was important to me. I wasn't looking to make new friends by donating and felt the bond between a donor and recipient might be an awkward one. All that was important was the NHS putting my 'spare' kidney to the best possible use. I know that other donors are divided, some feeling the way I did, whilst many others would very much like to meet their recipients.

It was six months earlier when I received an anonymised letter from Terry. He thanked me, explaining how the transplant had not only changed his life but the lives of those closest to him. He was now able to enjoy golf and delivered meals on wheels twice a week. In short, it gave him back his freedom from the ties of dialysis to enjoy family life. Terry also expressed the desire to meet me.

I did not want to meet. The letter was wonderful but I didn't want the emotional ties that would come with a meeting. I took four months to think this through. I tried to put myself in the shoes of Terry and other recipients, realising that being a recipient of an anonymous living donor could be very perplexing. Just as many friends and family of donors can't understand how someone could donate a kidney to



someone they don't know, so recipients can feel the same way – only they are carrying that kidney within them. As I later learned, Terry wanted to know what sort of person would do such a thing.

If I could go through all that is entailed with donating a kidney, surely I could take a few hours to meet the recipient if it was important to them. And so I agreed to meet. I brought along my wife Hazel, and Terry brought along his Aunt Doreen – both absolutely delightful people. I was at ease immediately as my apprehension melted away. The couple of hours went by in a flash, exchanging perspectives and experiences as donor and recipient. Emotions were highly elevated, but controlled. Our meeting ended with an invitation from Terry to meet his children at a lunch hosted by Doreen, which happened a month later. I had no hesitation in accepting that invitation and am now looking forward to meeting Terry's grandchildren at a family BBQ later this summer.

Bob Wiggins

Sheffield students tackle organ donor shortage

Students from Sheffield University took part in an Apprentice-style project, designed to raise awareness of the real-life problem of organ donor shortage.

Second-year undergraduate students from the University's Biomedical Science department, applied their anatomical knowledge to tackling the issue of the shortage of registered organ donors in England.

The students were split into small teams and each given the task of creating an effective campaign, targeted at encouraging more young people to sign up to the organ donor register.

Project creator, Dr Lauren Buck, said: "The students were encouraged to consider factors such as sustainability, finance and potential collaborators within their campaign and were given total creative freedom. The amount of effort put in has been astounding and has shown incredible sensitivity and maturity to issues such as faith, ethnicity and communicating with young adults".

"We hope that by embedding enterprise education into the anatomy curriculum, students will gain new skills and an insight into how their subject-specific knowledge can be used to communicate with the public on important issues."

The students benefited from expert lectures on campaign planning, target audience profiling and the creation and maintenance of mutually beneficial partnerships.

The three most innovative and impressive groups, whose work included app storyboards, postcard scratch cards and collectible t-shirts, were chosen to present their work in an Apprentice-style final lecture attended by representatives of the NHS and a local marketing team.

Student Rebecca Jones said: "We were actively encouraged to ask questions, consider anatomy in a wider context and develop skills wholly necessary both during study and beyond. Dr. Buck's project has provided students with a valuable opportunity to obtain and develop these skills."

The project was a joint venture between the University, The Children's Hospital Charity, and the city's NHS Blood and Transplant centre.

From an article in *The Star* on 13 May 2015

Swindon businesses raise more cash for kidney donation

An event organised by Swindon businesses has raised £2,535 for Give a Kidney.

The East Meets West event gave families a flavour-filled taste of the East in March. It was held at the Punjabi Community Centre and hosted by Swindon businesses The Sales and Marketing Hub and Kam's Motor Clinic, with Charanjit Dhaliwal, who's invaluable support has been backed by her employer Barclays Bank, who generously contributed £1,000.

DJ Gamma played floor-filling tunes from Bhangra to Bollywood, from the 70s to the present, and a delicious hot Punjabi buffet was served.



The event was supported by the following generous local businesses: Aerial Imaging Solutions, Amy's Hair & Beauty, Asset Guardian Company, Castles Estate Agents, CentraHeat, UCcert Limited, DC Computers, Healthcare Solutions, Ideal Displays, MLL Print and Digital and Mortgage Advice Bureau.

Jasie Rai, Director of the Sales and Marketing Hub said: "We held a charity night for Give a Kidney back in December 2013. It was such a success, we decided to do it again. The event was fantastic and I would like to thank everyone who contributed to its success."

Jasie has only one kidney herself, having had one removed. She has a pyeloplasty on the remaining kidney and may eventually need a kidney transplant.

Chris Burns-Cox of Give a Kidney said: "We're very grateful to Jasie for creating this event and to all the businesses and families who supported it. It was a memorable evening, and helped us to raise awareness of the need for kidneys from healthy donors."

There are currently more than 5,500 people on the waiting list for a kidney transplant in the UK, and around 300 people die each year whilst waiting for a kidney transplant. Humans only need one kidney, so if more healthy people came forward to give theirs,

My gift to someone else's family

Out of the blue in May 2009 our youngest son Oliver, at the age of 27, was diagnosed with acute renal failure. He had only 3% kidney function yet the week before he had been busy digging his vegetable garden! There followed many anxious months as he went onto dialysis and his elder brother Caspar was worked up to give him one of his kidneys.

During these months we were all looking forward to a two week holiday, to celebrate my husband's retirement, in Javea, Spain. But we were worried that the holiday could not go ahead with Oliver on dialysis. To our delight and amazement the NHS team in Hull arranged for him to undergo dialysis on alternate days at a clinic in Denia about half an hour away from our resort. So the whole family of 10 had an amazing fortnight in the sun, taking it in turns driving Ollie to and from Denia.

On 23 March 2010 Oliver and Caspar went into theatre at St. James's hospital in Leeds for the kidney transplant. The whole family are delighted to announce that four years on, both young men are doing wonderfully as the operation was a success.

This was also the start of my own journey. I had been prepared to give my son one of my kidneys so why not investigate if I could do the same for someone else? After initial enquiries I began tests in December 2012 to see if I was a viable candidate. Many months, tests and investigations later I was admitted to Birmingham University hospital as an altruistic kidney donor. Within three

days I was home and I began the road to recovery, knowing only that my kidney had given hope to a 40 year old man.

In December I received a small package. Was it a Christmas present I wondered, and in a way it was. I had been sent a silver brooch. Designed by Liz Welch it is a distillation of the essence



The whole family celebrating in Spain. Ollie is 2nd on the left and Caspar 5th on the left. Altruistic donor Joanna is 2nd from the right.

of the gift of a kidney - hope and life. The brooch shows two figures embracing across an anchor (hope) or Egyptian ankh (life). I treasure it and wear it with pride.

Throughout both these journeys the Renal Nurses were amazing. The support they offered was quite extraordinary. Both as a mother concerned about her son and as a donor I have always felt there was someone to turn to. After a year preparing to be a donor and then a year of being looked after at regular intervals by my Renal Coordinator, I miss her!

I now give talks to local WI groups about my experience. The main aim is to encourage people to go on the Organ Donor Register. Not only to do that, but to have the important conversation with their families about their wishes so that in the event they are not overruled. You never know, I might even inspire someone to be a kidney donor!

Joanna Ewing

Look out for Give a Kidney's new website, which will be launched shortly! Also, consider adding a poscript to your emails to help promote Give a Kidney, such as: **RENEW A LIFE - GIVE A KIDNEY** - please see www.giveakidney.org If you are a Twitter user, please find every opportunity to tweet or retweet anything related to kidney donation and including Give a Kidney's website.

Contact us

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