



Give a Kidney celebrates a new milestone: Britain's 250th altruistic donation

Of the 3,000 kidney transplants performed in the year to last April, a few more than 1,000 organs came from living donors, typically the relatives of the recipients. Only 76 of these were strangers who had volunteered to make altruistic, or 'non-directed' donations. Very few will know what became of their kidneys.

Give a Kidney is the only charity in this field, and in February this year celebrated the 250th altruistic donation performed since the practice became legal in 2006. The need for new donors is urgent; of the 6,000 people in Britain waiting for a kidney, 300 can expect to die this year - almost one every day.

Press releases to mark this encouraging milestone have resulted in lots of news coverage up and down the country, including on Daybreak, articles in the Independent, Metro and many other local papers. It is hoped this will attract more potential donors or at least get people talking about the subject and understanding the facts.

Altruistic donations are increasing year on year. In 2013 the figure was 107, a 78% increase compared to 2012, and the latest statistics from NHSBT show that there were nine new altruistic donations in January 2014 alone.

Musical Extravaganza in Glasgow for Give a Kidney

It's a double 'thank you' from Give a Kidney to Scottish brothers Paul and Kenny Dooley.

In 2012, Kenny donated a kidney and has since raised a massive £40,000 for kidney research.

Inspired by his older brother, Paul is considering donating a kidney himself, and is busy organising a charity nightclub night for Give a Kidney on April 26th.

Great club DJ's have been lined up, and Scottish company The Edrington Group has agreed to match-fund whatever is raised, which could be quite significant.

Jan Shorrocks, Public Relations Officer for Give a Kidney will be attending the event to say a few words about the charity's important work. Paul explains how the fund-raising initiative grew:

"My idea started off as a small event but with the interest and support of a few friends it has escalated into something I never thought I was capable of putting together. I have a fantastic DJ Line-up which includes Craig DZ Mathews (born



with only one kidney) who is current director of Indigo Music Limited, Stu McLean who is the resident DJ in Glasgow's Victoria's Nightclub, DJ Shabz, particularly known for his time in Silver which was no doubt one of the best clubs in Glasgow, and George Bowie - the main dance DJ from Clyde Radio - which is absolutely

awesome!"

The event will be at The Clydebank Town Hall and Ross McIntosh at AVL Scotland will be providing all Sound and Lighting on the night, meaning the DJs will be using the best equipment and the guests will be blown away with the fantastic sound and lighting on display.

There will be some great raffle prizes too. Paul hopes to raise as much money as possible and says he "will be putting 100% effort in to achieving a successful event for what is a fantastic charity."

If you know of any potential sponsors for Paul's event, please let him know by visiting his Facebook page (Paul Dj-Dooley).

Huge thanks to both the Dooley brothers for their energy, enthusiasm and support for Give a Kidney.



Organiser Jasie Rai, with Give a Kidney Chair Chris Burns-Cox

LOCAL BUSINESSES IN WILTSHIRE SUPPORT GIVE A KIDNEY

Jasie Rai, Director of The Sales and Marketing Hub based in Swindon, hosted a Ladies' Charity Night of delicious Indian food and entertainment to raise money for Give a Kidney at the Supermarine Sports and Social Club in South Marston, Swindon. It was a memorable evening, raising £3,006 - but just as importantly, raising awareness of the need for kidneys.

The event was sponsored by Jasie's company, with help from many local businesses including Barclays Bank, Swindon Sikh Temple and Punjabi Community Centre, Kam's Motor Clinic, The Khyber Restaurant, MLL Print and Digital, Cross Street Cars and others. The Sales and Marketing Hub offers B2B lead generation and business development using an intelligent non-scripted telemarketing approach to any companies looking to grow their business in the UK.

Jasie said: "As someone with one kidney following a nephrectomy on one and a pyeloplasty on the other, I understand the urgent need for more people to consider donating kidneys. Humans only need one kidney so if more healthy people came forward to give theirs, more lives could be saved."

Jacquie and her kidney's final journey together

Jacquie Dowding considers herself lucky. 26 years ago she underwent a kidney transplant from a deceased donor and that kidney is now near the end of its useful life. Her sister and boyfriend have offered her one of their kidneys as a replacement.

She and her partner Tony and friend Shariff set off for Panama via Southern Mexico, El Salvador and Costa Rica at the end of January this year on their yacht *Windstrutter*, captained by Tony.

With her decreased kidney function this trip is a tough one but Jacqui sees the bright side, commenting:

"I feel the motivation to do [the trip] and live is greater and hope that I make Panama and then the next leg and the next, culminating in an Atlantic crossing. However, plans are written in sand and the journey is not the destination".

Jacquie hopes to raise awareness of organ donation and transplantation and money for South East Kidney Patients' Association for each leg that she completes. To read more or follow her progress, you can visit her Facebook page or follow the link to her fascinating blog at www.travelpod.com/member/windstrutter



Please help us spread the word

- add a footer on your emails eg. 'Visit www.GiveaKidney.org - the charity raising awareness of altruistic living kidney donation'
- tweet and re-tweet!
- like the Give a Kidney Facebook page or post a comment on your own page
- use sticky labels to put on envelopes - available from suzannadendulk@googlemail.com

Woman of 85 is oldest kidney donor in UK

An 85-year-old woman has made medical history by becoming the oldest person in the UK to donate a kidney while still alive.

The pensioner, now 86, who wants to remain anonymous, made the selfless act and gave one of her kidneys to a complete stranger after saying: "Why do I need two kidneys to sit at home knitting and watching television?"

The woman decided to offer one of her kidneys for donation after reading about the desperate need for people to donate their organs to help those on the NHS waiting list.

The woman has recovered well from the procedure and has absolutely no regrets and is hoping that by showing she has done it at her age, she will encourage other people to think about becoming an altruistic donor.

"I had two kidneys, but I knew I could survive perfectly well with just one. So I thought why not give one away to someone who needs one while I am alive rather than waiting until after death to donate my organs."

After tests revealed the woman was fit to go ahead with the procedure and

approval had been given by the Human Tissue Authority, her kidney was offered to the "donor pool" in the same way as a kidney belonging to a deceased person.

Studies have shown that a living donor kidney usually performs better, works quicker and lasts longer than one from a deceased donor.

Once a match was found for the woman's kidney, a date for surgery was set between the two centres and the woman's kidney has now given a stranger a better quality of life.

Fiona Biggins, transplant recipient co-ordinator at Lancashire Teaching Hospitals NHS Foundation Trust, said: "There is no age limit when it comes to organ donations, although each potential donor has to be assessed on an individual basis.

"We are always extremely grateful to all those who consider making this generous offer. This lady has been incredibly kind by donating her kidney at the age of 85 to a complete stranger and she is a real inspiration. She is a very traditional

and matter-of-fact woman and we have thoroughly enjoyed caring for her."

There are around 6,000 people waiting for a kidney transplant in the UK and one person dies almost every day while waiting for an organ.

Since April last year, Lancashire Teaching Hospitals has dealt with 43 deceased donor transplants, 27 live donations (with another four planned) and seven altruistic donations from other centres.

Chris Burns-Cox, Chair and co-founder of Give a Kidney, and a retired physician, explains:

"When considering a person's health status it is not the age that matters but the number of expected years to come. An 85-year-old may very well be fitter and healthier than a 65-year-old. Each potential donor receives a very thorough health check to assess their suitability as a donor.

"The number of altruistic donors in the UK is increasing steadily year-on-year as more people become aware that this is something they can do with minimal risk."

Taken from an article published in the Lancashire Evening Post



On 20 March, altruistic donor Anthony Goulder gave a short talk about altruistic non-directed kidney donation at the Golf & Country Club in Exeter. The occasion was an NHS Blood and Transport public awards ceremony, and Anthony had achieved the milestone of 100 blood donations. The audience of some 70-80 people included a few NHSBT staff. He welcomed being invited to give the talk, and commented:

"In discussing kidney donation afterwards with the others sitting at my table, no one had heard of the concept of altruistic donation".

That's perhaps predictable at this moment in time but it's a situation that is changing, thanks to all the media coverage over the last two years especially - since the launch of Give a Kidney in 2011 - and all the volunteer speakers, many of whom are donors themselves, who have given their time and energy to spread the word about the charity and its aims.

Ride London 2014, here I come!

After missing the Ride London cycle event last year due to a crash, I am back in training for this year's event. Nearly two years on from donating at Queen Alexandra in Portsmouth I have no regrets, in fact the opposite. The rise in the number of altruistic donations is very exciting. We all hope that by our example more and more people will come forward, maybe we really can eliminate the waiting list so that no-one is on dialysis or dying for want of a transplant.'

David Rang



Kidney donation: What are the risks?

The kidneys are the body's filtering system. They take waste products from the blood and excrete them in urine. Although most people are born with two, it is safe to live with one.

"As with all operations, there are some risks but these are usually involved in the process of removal and not at being left with one kidney," says Paul van den Bosch, a GP in Surrey with a particular interest in kidney disease, who has himself donated a kidney. "The remaining kidney will naturally increase in size and levels of waste products in the blood quickly return to normal."

According to the NHS, there is an 85 to 90 per cent chance transplants from deceased donors will work well after a year. For living donors, it's slightly higher: 90 to 95 per cent. 'This is because living kidneys are in a better condition and because the operation can be planned,' says van den Bosch.

While there is a one in 3,000 chance of

death for the donor, van den Bosch says to bear in mind that the risk of an average man in his mid-fifties dying in the next year is about one in 500. "In the year of the

"The risk is real but low - about the same as crossing the road after a pint of beer."

operation, he would be far more likely to die from an unrelated cause than from the operation," he adds.

There is a slight risk of increased blood pressure or excess protein in the kidney but van den Bosch says studies show no long-term effects. Kidney transplants also save the NHS money, as dialysis costs around £20,000 a year per patient.

Altruistic donor Chris Burns-Cox, retired physician and co-founder of Give a Kidney adds: "The risk is real but low - about the same as crossing the road after a pint of beer."

SUPPORT FOR KIDNEY PATIENTS:

The British Kidney Patient Association (BKPA) funds short breaks and holidays

Adults and families affected by kidney disease and unable to pay the full cost of a holiday can apply to the BKPA for a grant. Every year BKPA funds over 350 short breaks and holidays for kidney patients.



The grant can be put towards the cost of a holiday in the UK or overseas, arranged through a travel agent or through a specialist travel company such as Freedom Holidays which also organises dialysis.
www.britishkidney-pa.co.uk

Did you know?

- ▶ The kidneys have a higher blood flow than even the brain, liver or heart.
- ▶ Each kidney is about 4 ½ inches long and weighs approximately 4 to 6 ounces.
- ▶ Adults have around 7-8 litres of blood, which is constantly filtered by the kidneys, as much as 400 times per day!
- ▶ Every day 50 gallons of blood are filtered through 140 miles of tubes and millions of filters within the kidneys.
- ▶ Your kidneys are also responsible for keeping things in your blood balanced - acid, electrolytes such as sodium and potassium, sugars, and proteins. An excess of milk or antacids may cause kidney stones.
- ▶ Your kidneys are responsible for activating the vitamin D that is produced when you are exposed to sunlight.
- ▶ The kidneys reabsorb and redistribute 99% of the blood volume; only 0.1% of the blood filtered becomes urine.
- ▶ The kidneys of a newborn baby are about 3 times larger in proportion to body weight as in the adult.
- ▶ The volume of urine excreted daily varies from 1000 to 2000 ml (1 to 2 litres).
- ▶ If you lose a kidney, your remaining kidney can increase in size by 50 per cent within two months, to take over the job of both.

From a donor's perspective...

"At first, my wife asked me not to do it. But when she looked at the research and saw people online begging for help for their young children, she changed her mind. She was hugely supportive because if that was our child, we would want someone to help."

Kenny Dooley, who donated in 2012

"It seemed to me that you could convert somebody's life from major misery and early death to normal again. It seemed like the most useful thing I could do."

Chris Burns-Cox who donated in 2010

"Everyone is someone's mother, brother, friend. Just because it's not your family member doesn't mean they deserve it any less."

Clare Bolitho, who donated in 2011

"Altruism is a very difficult word. It means being totally selfless and I'm not sure that that exists. Most acts, however selfless they may appear, that person who's doing it actually gets something back. I've done this and I will take that through with me for the rest of my life - and that's a really good feeling!"

Teresa Dobson who donated in 2013

"I think a lot of concern is that, you know, we were given kidneys for a reason and that it's unsafe if you don't, but all the evidence is, if you look at people who have only one kidney, who donated a kidney, it certainly doesn't seem to preclude a long and healthy life."

Paul van den Bosch who donated in 2008

Taking Organ Transplantation to 2020 - a new strategy

The UK wants to become a world leader in organ donation and transplantation, and with that aim in mind **Taking Organ Transplantation to 2020 - a UK Strategy** was launched during National Transplant Week last year. The strategy states that the UK can and must do more to save and improve lives through organ donation and transplantation. The NHS still does not support some people who want to donate and more can be done to ensure that donated organs are used.

The NHS needs to build on the excellent progress achieved in the past five years, pursue consistently excellent practice in the care of every potential donor and maximise the use of every available organ. Getting it right every time in hospital, however, will not be enough. Unless people in the UK are prepared to donate their organs when and if they can, and families are proud to agree to donation when their relative's wish is unknown, these aims cannot be achieved.

The strategy contains a series of recommendations which aim to enable the UK to match world-class performance in organ donation and transplantation by improving on existing achievements such as a 50% rise in deceased donation rates since 2008. It has the backing of all four UK health ministers.

The new strategy aims to improve consent rates to organ donation and increase the number of patients receiving a transplant. It calls for a revolution in public attitudes and behaviours, a reminder of how important it is for individuals and their families to support donation whenever they can.

You can read more about the strategy at:

www.nhsbt.nhs.uk/to2020/the-strategy

Living donation in Europe

Lisa Burnapp, Lead Nurse for Living Donation at NHS Blood and Transplant recently attended a conference in Europe on the subject of altruistic non-directed donation. Interest seems to be growing within Europe: Paul van den Bosch, a GP and Steering Group member of Give a Kidney, was invited to take part in a TV programme in Denmark. In February he also participated, along with fellow altruistic donor Sanjiv Gohil, in a news programme on Ukrainian TV made by the British Office of the Ukrainian TV channel 'Inter'.

Even more recently, Give a Kidney has been approached by a German TV channel looking at the charity and the subject of altruistic donation, and two UK producers are currently planning to make a documentary about altruistic donation.

Advances in promotion of cadaveric and living donations in Europe

There have been successful efforts in the promotion of donation after death, particularly in the south of Europe. In Croatia, for example, a few years ago there was a rather small number of cadaveric donors but now they are even ahead of Spain thanks to new legislation and a lot of political efforts. However, even in these countries, the number of deceased donors is not sufficient as the dialysis-dependent population is increasing even faster, partly due to medical advances allowing more elderly patients to receive permanent kidney replacement therapy.

In the last few decades the number of living donations has significantly increased and a concerted political effort seems mandatory to establish better donor rights and protection throughout Europe. There is no Europe-wide programme for altruistic donation. The major reason for this is the current health policy within Europe: While some countries have

a state insurance covering everyone in the same way, paid by taxes or common health insurance, some have individual solutions. In those countries with a general health policy, it is rather easy to support the donor; all costs are covered. In other systems, it is the health insurance of the recipient which covers the costs. Thus, in some situations, the donor is in doubt which health insurer is covering which part of his problems. The donor may sometimes even have a problem getting covered at all; in Germany, for example, living donation is considered a cosmetic operation, so costs for the treatment of problems arising from donation long term such as a hernia operation or even dialysis may not be covered.

Furthermore, there may be financial damage to the donor by higher costs for insurances or loss of work or even a prolonged recovery. The way to deal with these issues differs from country to country. In some countries, such as Denmark, there may be a law by which insurers are required to offer identical policies to donors as to non-donors. Why such a law is not implemented in all countries is a matter of debate as discrimination for race, religion, sex or age are not allowed within the European community, enforcing similar policies in all matters of private and social life.

Today, the steps being taken to strengthen donor rights are somewhat small and half-hearted. The only step taken by the EU is the implementation of a donor registry. It has not been explicitly stated for what period a donor has to be followed. In some countries, the follow-up stops with release from the hospital, in some after one, two or three years. Only in very few countries are donors mandatorily followed for life, as altruistic donors are in the UK.

Source (in part):

State of Living Kidney Donation in Europe, Uwe Heemann and Lutz Renders 2012

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