

Growing numbers of people would consider donating a kidney to a stranger

New data from polling specialist YouGov suggests that 11% of the adult UK population would consider giving one of their kidneys to someone they do not know whilst they are alive – a considerable increase of 3% since a previous YouGov survey three years ago. The survey also revealed a dramatic leap in the levels of awareness that a UK adult can legally donate a kidney to someone unknown to them – with the numbers of people aware of this increasing from 67% of the adult UK population in 2011 to 79% in 2014.

The survey was conducted on behalf of Give a Kidney. Dr Chris Burns-Cox, Chair of the charity, said: "These figures are hugely encouraging. Give a Kidney was established in 2011 to help raise awareness of altruistic kidney donation, with the aim that more people would consider coming forward to help someone in need. These figures suggest that our work is already helping to make a significant difference.

"The 2014 data suggests that 11% of the population would consider giving a kidney to a stranger. If just a small proportion of these came forward to donate, there would be enough available kidneys for every person currently in need of a kidney in the UK! At the moment there are almost 6000 people awaiting a kidney transplant in the UK and around 300 people die each year in need of a kidney. A kidney from a live donor not only works better and lasts longer than one from a deceased donor, but the surgery can be

planned in the very best of circumstances for the donor, recipient and surgical team. Each successful transplant also saves the NHS an average of £20,000 per annum, meaning that a single kidney could save up to £200,000 in the first ten years alone.

"We're delighted that our activities and those of others like us, are raising awareness and encouraging and supporting more and more people to consider making this life-changing gift. We applaud the 323 people in the UK who have already donated one of their kidneys altruistically and we will continue to work hard to ensure that even more people will be encouraged to consider whether it is something they are able to do."

Lisa Burnapp, Lead Nurse for Living Donation at NHS Blood and Transplant said:

"These figures from YouGov have come at the same time as the launch of our Living Donor Kidney Transplantation 2020 strategy. The aim of the strategy is to increase the number of people who make the decision to donate a kidney to others that need them.

"Altruistic kidney donation increased by 55% in the past two years but there is still a long way to go. We appreciate all the work that Give a Kidney does to raise awareness of living kidney donation, as without their tireless campaigning this figure would be lower than it currently is. We will continue to work closely with charities, hospitals and other groups to ensure that by 2020 we hit our target and match world class performance in living kidney donation."

First steps towards becoming an altruistic kidney donor

If you are considering donating a kidney altruistically, or would simply 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, which has detailed information about all aspects of living kidney donation).

If you would like to discuss the possibility of donating a kidney before you contact a transplant centre you can get in touch with us at giveakidney@gmail.com and visit www.giveakidney.org - or you can contact us by post at:

Give a Kidney, PO Box 65885, London N7 1BR.



Give a Kidney AGM & Conference 2015

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

Details to follow, but please note this date on your calendar.

New UK strategy to match world class performance in living donor kidney transplantation

A new strategy to achieve world class performance in living kidney donation was launched last month. It set the agenda for increasing living donor transplants, from 18 transplants per million population to 26 transplants per million population.

One of the aims of the strategy is to try and prevent patients going onto, or minimise the time spent on, dialysis prior to transplant. Where possible, it's important that patients have a planned transplant before they have to go on dialysis as this results in a far better outcome. An increase in living transplants could help this happen.

From 2000 to 2010, living donor transplant activity in the UK trebled - there were 4,199 living donor kidney transplants, 253 paired/pooled transplants and 256 non-directed altruistic donors. Read more at: www.kidneyresearchuk.org/news

you don't have to die to donate a kidney



Keeping you informed

It's been just about a year since I took up the post as PR Officer for Give a Kidney so we thought it might be useful to take a look back on the last few months.

Over the last year I have very much focused on PR and media as the most cost effective way to get to a large number of people and I've been pleased with much of the great coverage we have received. In the last three months alone Give a Kidney has been represented in the following outlets: six-page piece in the Observer Magazine, full page in the Sunday Telegraph (in fact donor Claire Ramsden was on the front cover of most editions!), an interview on BBC Radio 5 Live, pieces in a number of Women's magazines and a 40 minute slot on Ujima Radio in Bristol, focusing on non-directed donation in the Black and Minority Ethnic Communities. I'm currently working on a piece with the Express and focusing on Men's lifestyle magazines. As I write, BBC Scotland are filming a documentary with a potential donor.

I'd like to say a big thank you to all of the members who have been willing to share their stories with the world – it simply would not be possible without you.

Members have also been successfully placing their own PR with pieces on the Jeremy Vine Show, Take a Break, Women and Home, Daily Mail and Daily Mirror and

more popping up. A few people have asked for some tips on getting their story featured. It's probably easiest to try your local news outlets first and the NHS have recently put together a sheet especially for this which will be available on our new website. We



have also included tips here, as an article on page three of this newsletter. If any of you wish to gain publicity about your kidney donation please let me know and I will do my best to help or advise.

Alongside that we're currently working on a new website, making new links with other charities and working closely, as always, with NHSBT. We had a stall at the British Transplant Games, which was fabulous and our new T-shirts, designed

by member Sue Gianstefani, went down a storm (see page three for details of how to get yours). Thank you Sue! We'll also be represented at the National Kidney Federation Conference in October. Do pop by and say hello if you are attending.

As some of you may know, Give a Kidney New Zealand was established last year, and just today we've been having conversations with a non-directed donor who wishes to set up a similar organisation in the USA. We've had some interest from European news outlets and stories in their media, so we're also starting to make links with other European countries in the hope that we may be able to influence their policies. As part of that I'll be attending the European Congress on Organ Donation later this month to make new connections and help spread the word about the UK programme.

I anticipate that it's going to get more and more difficult to gain significant media coverage in the UK, as altruistic donation continues to become more commonplace, so beginning to look beyond the UK seems like a sensible way forward. It has been a busy few months but I'm enjoying helping to spread the word, and it's always a delight hearing your own stories. Please do continue to keep sharing them with me and others!

Jan Shorrock

Luc Delauzun and his one kidney are set to run 160 miles across the Egyptian desert

Three years ago Luc Delauzun, who was then only 25, was one of the youngest people to donate a kidney to a stranger.

Still just as committed to the cause, Luc wants to continue to raise awareness and funds for Give a Kidney, and he recently gained a place on the Ocean Floor Race which takes place in March 2015. This is a gruelling four-day marathon of 160 miles in blazing heat through Egypt's Western Desert and White Desert, part of the Sahara. That's the equivalent of running more than six marathons back to back!

On the plus side, it's said that the Ocean Floor Race traverses one of the most beautiful, surreal landscapes on the planet - so named because millions of years ago the White Desert was a sea-bed. Each runner will navigate using a gps device and there are checkpoint tents every 15 miles where they will have access to water, food and their pre-filled drop bags. For more information about the race, see oceanfloorrace.com

Luc will be doing mini fundraising initiatives throughout the year running up to the event. Clearly his remaining kidney must not be put at risk by undertaking the race and the intensive training it will require, but his doctor has given him the thumbs up and will be managing his hydration carefully throughout.

Give a Kidney wishes Luc every success in this amazing adventure and gutsy challenge. He'd like to raise £2,000, so please show your support by visiting his JustGiving page and making a donation.

www.justgiving.com/Luc-Delauzun



OCEAN FLOOR RACE

Talking to the media: tips

Our colleagues in the NHSBT press office have put together a TIPS sheet on approaching the local media, so we thought it would be useful to run through some of the key details here. Thanks to them for being willing to share with our membership.

If you want to share your story, please do contact our PR Officer, Jan Shorrocks, who is happy to help you wherever possible and appropriate. It's also good for us to know before stories appear in the media so we can let local co-ordinators know they might have more enquiries than usual. She's on jan@glowlife.co.uk

- The first thing to do is identify the media you want to approach, whether it is print, radio, TV or online media, and find an email address, phone number or address for the newsdesk.
- It is best to give them a simple summary of your story straightaway so you can gauge their interest – eg, I gave a kidney to ... and I wondered if you wanted to tell my story as I'd really like to encourage others to transform lives. Explain why you made the decision to donate etc.
- They should be able to tell you quite quickly whether this is something they are interested in or not.
- They'll want to get more details, your name, age, hometown, family details, why you gave a kidney.
- If they are interested in covering your story they'll want to do an interview and perhaps interview you on camera or take photos. They will ask you questions about your story and it will just be for you to tell them in your own words about what happened.
- If your story involves someone else – a relative or friend – they may want to include details about them and possibly interview them and include film footage or photos of them too. Do check they're happy with you sharing your story before you do so.
- If you donated to or received a kidney from a stranger, please avoid giving the exact date of your donation – a month and year is the most detail we recommend. This will help ensure that your donor or recipient doesn't find out about you if they are not ready to do so.
- As you know from your own experience, living donors are stringently assessed before being accepted as a donor and any surgery going ahead to minimise the risks. It would be great if you can make sure you explain how you were assessed and how any risks were explained to you.
- Don't worry about official statistics or information – they will go elsewhere for that – a hospital, the Human Tissue Authority, NHS Blood and Transplant or to Give a Kidney.
- If the media you approached aren't interested in covering your story, don't be disheartened. There are other things you can do to help promote donation – your local hospital may hold awareness raising events, you could give a talk to a local group or school or you could write a letter to your local paper and see if they'll print that instead.
- Wherever possible please encourage the journalist to include the website www.giveakidney.org so interested people know where to look for more information.

Good luck!

Give a Kidney Tshirts

In addition to the Tshirt with the Give a Kidney logo (Geoff Roberts is pictured wearing one on P.4), member Sue Gianstefani has designed an eye-catching new Tshirt for the charity, pictured here, helping to spread the word in a fun way! Thanks Sue.

They cost £10 each (inc UK postage) and you can order one through the charity's Administrator Suzanna at suzannadendulk@googlemail.com



Staying alive: Dialysis & kidney transplant survival stories

edited by Alan & Jan Cooper



Photo: Andy Ford, Infinite Skydiving Solutions

By collecting these stories into a publication, the editors Jan and Alan Cooper aimed to raise awareness about the many challenges faced by sufferers of kidney disease, which is a growing problem for society and for the already stretched NHS. But in telling these stories they also highlight the positive spirit many kidney patients demonstrate in their day to day lives which are often blighted by pain, lack of energy, food restrictions and so many basic things that most of us take for granted. One particular manifestation of optimism in the face of all the odds is 30 year old Maddy Warren's piece called 'Living to the Full'; she is pictured here freefalling from 12,000 feet! The subtitle of this book is 'Dialysis & kidney transplant survival stories' - but this is about more than merely surviving or coping, it's about the fortitude and courage of people to make the most of their lives, whatever their circumstances.

As Sandra Currie, Chief Executive of Kidney Research UK, says in the Foreword to the book: "You will read how people in their own way have come to accept that their life has taken a different path to one they would have mapped out for themselves. Often a path they would never have chosen. Some of the authors are patients, others are partners. Some of the stories are fiction, others are real. Each of the pieces gives insight into how we can all explore and learn to understand and find ways to adapt to the unexpected and often unwelcome turns on our path through life."

Book price: £6.00. eBook: £1.44
www.thestayingalivebook.co.uk
All profits go to Kidney Research UK

Walking the Via Francigena

Altruistic donor Geoff Roberts tells why he plans to walk 2000 kilometers, raising awareness for Give a Kidney



Earlier this year I donated my left kidney to a stranger. It was the culmination of a journey lasting two years during which I learned a lot about myself.

This year I'm planning a journey of a very different kind: Next spring I am walking with a friend from Canterbury to Rome following the ancient pilgrim route called the *Via Francigena*, which ends in Vatican City. I want to do this for *Give a Kidney*, mainly to show people thinking about becoming donors that you can not only lead an ordinary life after donating but an extraordinary one too.

The *Francigena* is almost 2000 kilometers from Canterbury to Rome taking in the Great St Bernard's Pass in the Alps, which is roughly the halfway mark. We will be staying in special pilgrim accommodation whenever possible and this is usually free, although donations are requested. We'll go past such places as Lake Geneva and Lausanne then Tuscany etc. All very beautiful.

We'll stay at the famous St Bernard's Refuge for a week to rest before attempting the second half of the journey. When we get to Rome, having collected rubber stamps in our 'credentials' (the pilgrims' passport) along the way, we will

receive a certificate at Vatican City to prove that we did the entire pilgrimage route.

I am not at all religious and lean more toward agnosticism. The companion I am taking with me is, however, and this is his life-long dream. If all works out as we hope and we arrive in Rome in good health, we intend to work on an organic farm for a month (WOOFing - a scheme where you work five hours a day in exchange for board and food). When we feel we have recharged enough, we'll attempt to carry on across Turkey and on to Jerusalem. From there... no decisions, except to relax and feel good!

By then my recent operation will be a distant, though significant, memory. I won't say it was an easy decision to give my kidney because it wasn't. My children were the most vociferous in their objections, fearing that if their kidneys failed in future I would have given away the spare that could have saved them. Mine might not have been a match anyway, but this was a very valid argument which I could only counter by saying that someone out there was not enjoying the luxury of hypotheticals but real life-and-death urgency.

I reasoned that by then the *Give a Kidney* charity would have gone from strength to strength with their pioneering work promoting altruistic donations, and my offspring would be in the enviable position of choosing from a list of viable donors. This last bit was hopeful I admit, but not entirely unreasonable given the way the numbers of altruistic donors have accelerated in the last few years.

I won't pretend I hadn't been frightened myself about my operation either. But I had put my name forward because it was something I strongly believed in and to have changed my mind through fear would have left me wondering who I was. For my recipient, it was a very successful operation: This was what it was all about and I felt privileged to have been a part of something so special.

Geoff Roberts

We are currently redesigning the website to make it more contemporary and as easy as possible to navigate and update. We hope to have the new site live by the end of the year. We'd really like to include the personal stories of more of our members so if you are happy to share yours and have not already done so please contact jan@glowlife.co.uk

Paul Silcox received a kidney transplant in 1977, when he was 23, and went on to become a successful athlete. He was



shocked to discover some 30 years later that the donor was a young boy, the same age as his own son.

He tried to find the words to tell the donor family how grateful he was and that he appreciated how tremendously difficult their decision must have been. This proved almost impossible until it took the form of the song, with lyrics by his wife.

Profits from the sale of the CDs will be shared between NKf, Family Donor Network and Kidney Research UK.

The CD costs just £5 plus £1.50 p&p (Cheques made out to "Jog On Music") from: Jog On Music, PO Box 95, Brecon LD3 3BS. It is also available for download from various online outlets.

Letters to the Editor

Reader's responses to Newsletter Ed 9...

Dear 'Misanthrope, another name for 'Altruistic' Kidney Donation could be Nephrodonation, or even Nephro-altruist. Please don't be abashed should you be accused of 'saintliness'; I suggest you read Nicholas Crace's article in the Newsletter in which he states that some people might consider you mad!

Jeanette Hipsey (directed donor)

Regarding the letter from Apprehensive asking former donors how much pain they experienced post-donation: Did you know that there is a mentor scheme for people thinking of donating a kidney, where subjective, non-medical anxieties such as this can be aired? There is also the useful blog, set up by Di Franks, where you can post your own experiences.

See www.livingkidneydonation.co.uk

Contact us

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

www.giveakidney.org