

From small beginnings...

You never know what might transpire just by having a chat with someone about your donation experience or your belief in signing up to the organ donor register. Sue James (inset) from Scotland did just that. After several discussions with a pub customer, he has now started the donation process at Royal Infirmary of Edinburgh!



Never underestimate what you have the power to do, simply by chatting to friends, neighbours, family.

Volunteer bookkeeper wanted!

The charity income in 2016 was around £20,000. Sometimes payments are made direct to our bank account, sometimes via Charity Choice, Just Giving or Paypal, to name a few. Each cheque and bank transfer must be carefully accounted for. Accounts are then summarised by our volunteer Accountant and sent to the Charity Commission annually.

Our Treasurer estimates that about two hours per week are required to keep on top of the bookkeeping and we wondered if someone might be willing to take this on. We are considering a subscription to specialist software to assist with the task.

The role would involve liaising with both our Treasurer and Administrator, so that membership fees are logged and donors thanked promptly. You will need to be confident with Excel and with downloading information online from the bank account. If you think you might be able to help with this, please get in touch in the first instance by emailing giveakidneyoffice@gmail.com



British Transplant Games

The British Transplant Games have been staged annually since 1978 in cities across the UK and this year will be held in North Lanarkshire, July 27th - 30th.

The Games are the flagship event of Transplant Sport, whose aim is to demonstrate and celebrate the benefits of transplantation whilst increasing public awareness of the need for more people to join the NHS Organ Donation Register and discuss their wishes with their families.

Many athletes go on to take part at the World Transplant Games.

Entries are open to all transplant recipients, donor families and the general public to take part in the 'Donor Run', taking place at Strathclyde Country Park Motherwell ML1 3ED at 7pm on Saturday, July 29th. There will be two races, a 3km and a 5km and the entry fees are £10 per person. Entrants can run, walk, crawl, skip or hop – there is a medal for all finishers!

Several from Give a Kidney in Scotland and England have signed up to take part. Volunteers from Give a Kidney Scotland who will be manning a stand at the event on Sunday at Wishaw will sport "Keep Calm and Give a Kidney" t-shirts. Please contact Colin McLachlan if you wish to volunteer.



Welcome to our two new Trustees, and a big thank you to our outgoing Trustee, Roger Corke.



Gill Owens,
PhD, CPsychol,
FRSA

Gill Owens is a chartered psychologist working in Teesside University Business School. She had over 25 years business experience across a number of industries before moving into academia.

Gill altruistically donated a kidney in 2015 and would do it again 'in a heartbeat' if possible. She feels passionately about the gift of organ donation and is pleased to be working with Give a Kidney to raise public awareness of non-directed kidney donation.



John Fletcher,
BVMS, Ph D,
FRCVS, FRAgS

John Fletcher is a vet, deer farmer and author living in Scotland. He gave a kidney to a stranger in 2009 and discovered that this was a hugely satisfying and rewarding experience.

He feels that if there was a more general awareness of the benefits that non-directed kidney donation offers to people of all ages we would see sufficient volunteers come forward to prevent anyone needing to die waiting for a kidney.

North London Donors Group

I went to the Give a Kidney Ambassadors launch meeting in June last year and signed up to join the team. When I heard one of the delegates speak about a group of Scottish donors that had been set up to spread the word it occurred to me that I could start my Ambassadorship by creating something similar in London.

I contacted Give a Kidney's Administrator, Suzanna Den Dulk, who kindly emailed London Give a Kidney members asking them to get in touch with me if they were interested in becoming part of this group. Ten people responded and eight of us met in the Tufnell Park Tavern in November 2016. We exchanged our kidney stories – most people hadn't met before – and established that almost all of us had been spurred to donate after reading articles or hearing radio or TV testimony from previous donors. We had all been inspired and were keen to inspire others.

We decided to approach various organisations and offer to talk to their members. Some were unresponsive but Kay Mason, the UK's first non-directed kidney donor, has now given talks in Welwyn Garden City to a lunch club and a school and has another booked for the autumn. We hope to identify more groups who are interested in our story.

The other idea mooted at the November meeting was to have a stand at the Royal Free Hospital on World Kidney Day, 9 March. We wore cheery T-shirts emblazoned: 'I gave a kidney – ask me why'. The stand was manned by Kay Mason, Veronica Plowden, Livia Prior, Peter Hodes and me

and although we weren't knocked over by a rush of people clamouring to learn about kidney donation, there was enough interest to justify our presence and you never know when the drip of information from different sources combines to promote action.

I'd like to move the group on again, so if any London donors – or, indeed, potential donors – would like to be part of this, do contact me at celiakent60@gmail.com. It involves infrequent meetings and provides support for flurries of action from time to time. I am sure there are lots of other ways we could help Give a Kidney's Executive Officer Jan Shorrocks in her untiring quest to get the message out there. On our own, it's a bit daunting but as a group, we can move mountains.

I have a connection with the Brandenburg Choral Festival of London and Give a Kidney was the chosen charity at a concert of Fauré's Requiem last November in the gorgeous Queen's Chapel of the Savoy. We were able to host a reception before the concert; I believe the total proceeds of the evening exceeded £1,000.

I have also maintained a friendly relationship with my transplant co-ordinator, Catherine O'Malley, at the Royal Free and she recently asked me if I would give a presentation to a community of Jains in Hayes. I learned that Indian communities have quite a high incidence of kidney disease but a conservative outlook on organ donation which this particular group is trying to address through informative talks from donors. About 200 people came to hear the talk and were eager to pick up our literature.

Celia Kent

Giles Smith - up for a challenge!

You have to be pretty fit to cycle two of Majorca's iconic cycling routes - well known in the two-wheeled world - Sa Calobra and Soller. But Giles Smith is fit (so fit that he opted to give his spare kidney away to a stranger in 2006). He has just come back from a week with his son after completing those gruelling ascents.

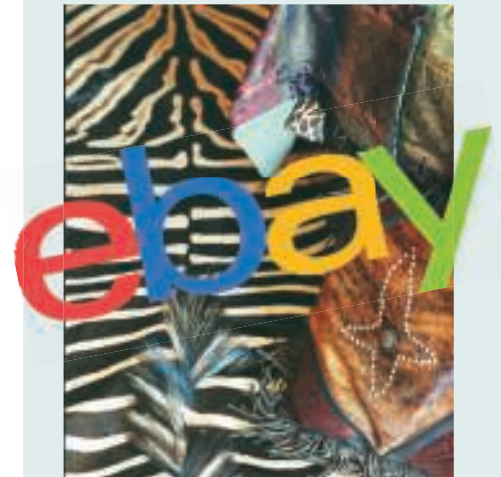


At 9.4 kilometres Sa Calobra may not be the longest climb on the island but it is

challenging with lots of hairpin bends, and has the most spectacular scenic views.

The second 'killer ride', as Giles describes it, is Coll de Soller, famous for its 61 hairpin bends. That part of the route is 5.8 kilometres, climbing 304 metres with an average gradient: 5.2%. One heck of a climb, and definitely not for the faint-hearted, but Giles and his son (pictured here) came in together, completing Sa Calobra in 51 minutes and Soller in 1.1 hours.

Selling on eBay to raise funds for Give a Kidney



We all have too much 'stuff! Have you considered having a clear out and selling what you no longer need on eBay? The charity has now set up a PayPal account, which means that it is now listed as a charity that can be selected to benefit from these eBay transactions. Phil Davison, recipient of an altruistic donor kidney, is doing a bit more than that! He tells us: "A friend of mine, a local Market Trader, indicated he wanted to give up his business and offered me his remaining stock at a peppercorn price and so that brings me to where I am now. I am still easily distracted and need to buckle down to working this stock. FYI (and please don't laugh too loud) it is mainly ladies' lingerie and vests etc BUT there are some household goods as well I hasten to add."

Phil is confident that "Anybody can sell on eBay or a dozen other internet platforms. A lot of them have simple to use FREE charity donation options. It isn't necessary to take loads of stock on board like I have – in fact the more personal the sale the more important the contribution. Instead of saying "I don't like that teapot any more" then chucking it out, if it is still in good order then sell it and donate anything from 10% to 100% of the sale value to this charity. It is all done automatically and the seller and the buyer do not have to do anything, other than complete the transaction."

We've even produced some flyers that you can send out with your goods, to say 'thank you' from Give a Kidney.

The financial year (2016/17) ended on a positive note with a small increase in the number of non-directed donors – 86 in comparison with 83 last year and more transplants achieved through altruistic donor chains.

Since I spoke to you at your AGM in March, work to develop the expression of interest form has continued and is close to completion. This will make it much easier for people considering donation to register their interest with a transplant centre and receive direct contact from a living donor coordinator. This month saw the release of the 'Let's talk about' series of films about living donor kidney transplantation. These were sponsored by NHSBT and produced in collaboration with Transplant TV. They can be found at: <http://transplant.tv/themes/lets-talk-about/>. There is one core film and seven short films, each looking at a different aspect, including 'donating a kidney to someone you don't know'. The films

are for everyone- patients, families and the public- and the aim is to get people thinking and talking about living donor kidney transplantation by seeing it through the eyes of donors, recipients and healthcare professionals. We have already received some positive feedback and are very grateful to those of you who gave up your time to participate in interviews and filming at your homes. Please use the films when you are talking to people or at your own awareness events and let us know what you think.

This year we continue to focus our efforts on increasing awareness and encouraging non-directed donors to donate into the kidney sharing schemes so that every donation creates as many transplant opportunities as possible. We look forward to working with you and other patient charities to achieve this.

Lisa Burnapp
Lead Nurse - Living Donation
NHS Blood and Transplant



Man can find meaning in life, short and perilous as it is, only through devoting himself to society.
Albert Einstein

Thinking about donating a kidney?

Get in touch with the Living Donor Co-ordinator Nursing Team in your closest kidney transplant centre for an initial chat (contact details on our website or the NHS Blood and Transplant website). Or contact us at giveakidney@gmail.com - we can help to answer any initial questions you may have and also put you in touch with previous donors who can tell you about their experience of donating.

Kidney Beauty Contest

Social media is being increasingly used by UK kidney patients to appeal directly for a donor. MatchingDonors.com, an American website, claims to find living altruistic organ donors for patients needing organ transplants. A BBC radio programme in May called 'The Organ Beauty Pageant' examined this claim and questioned the fairness of finding a kidney donor on the internet.

The transplant community fears a competition to attract donors amounts to an unsavoury 'beauty contest', in which only the most tech-savvy can participate. The knock-on effect is that these high profile donor-directed campaigns will be a drain on NHS resources as the would-be volunteers need to go through the rigorous and costly testing procedure – yet most won't turn out to be a possible match for their intended recipient.

Dr Adnan Sharif, a member of Give a Kidney's Steering Committee and consultant nephrologist at Birmingham's



Queen Elizabeth Hospital, admits that at times he and his team were completely overwhelmed by the demands that multiple volunteers, each offering to donate a kidney to a named individual, placed on the unit. He and his team were delighted for the individual who had a new kidney, but uncomfortable about diverting resources from patients who are waiting for an organ through the traditional routes.

As a consequence, clinical teams have voted with their feet and refused to deal with websites that allow kidney patients

to advertise for a prospective donor, unless no fees are paid. MatchingDonors.com doesn't charge UK kidney patients a fee but they do charge £460 to USA patients for a lifetime membership.

Over 100 UK patients and over 300 UK donors were registered at the site – yet in five years, not one transplant in the UK has resulted through this website, as patients have said that transplant teams simply refused to deal with it.

The former chair of the ethics committee of the British Transplantation Society, Professor Vassilios Papalois, argued that clinicians have autonomy and if they're not comfortable with the idea of a matching organ website, they're under no obligation to proceed. He found the idea of such websites ethically objectionable.

Have the 300 UK donors that have registered on the MatchingDonors.com website ever heard of Giveakidney.com I wonder?

Nicholas Crace

News from Give a Kidney Scotland



Tracey Jolliffe gave a TEDx talk in Portobello last month, which was well received. TED is a non-profit organisation devoted to spreading ideas, usually in the form of short, powerful talks of 18 minutes or less. TED began in 1984 as a conference where Technology, Entertainment and Design converged, and today covers almost all topics - from science to business to global issues - in more than 100 languages. Meanwhile, independently run TEDx events help share ideas in communities around the world.

This was an opportunity to spread the word about non-directed kidney donation and Tracey's talk was clearly a good piece of promotion for us.

The next meeting of Give a Kidney Scotland will be held on Wednesday 5th July at 6.30pm in the Hilton Edinburgh Grosvenor, 5-21 Grosvenor St., Edinburgh, EH12 5EF. All are welcome.

Information events in partnership with NHS Scotland

NHS Scotland have held several information events in hospitals to promote living kidney donations, Colin McLachlan gave a short talk on his donor experience at a seminar in Ninewells Hospital, Dundee and a similar event was held at Aberdeen Royal Infirmary with Alan Wallet. Further events are planned for the Royal Infirmary of Edinburgh on the 15th June, and Queen Margaret Hospital Dunfermline on the 22nd June, both with Give a Kidney representatives. It is encouraging to see that the NHS in Scotland seem to have become more active in promoting living kidney donation in recent months.

Review of the AGM and Conference, held in March

Bob Wiggins, the charity's Chair, welcomed guests to the AGM and conference, thanking Treasurer Sanjiv Gohil for arranging the meeting venue free of charge, saving the charity considerable costs.

Executive Officer Jan Shorrocks reported that 2016 had seen an enormous amount of media coverage, social media, events, fundraising and the forging of new partnerships, in particular collaboration with NHSBT such as the joint campaign around the 500th donation which had a reach of 18m from media alone. The Kidney Shaped Love campaign around Valentine's Day was NHSBT's first living donation campaign.

On Facebook the charity now has 1,800 followers and 974 on Twitter, we enjoyed our first viral post, reaching 170,000 users, when Celia Kent celebrated her 101 donations - 100 pints of blood and a kidney!

Traffic to our website is up 45% on 2015, with 136,975 visitors, 84% of these new. The peak was around the 500th donation campaign.

The Chair highlighted the need to find new ways to interest the press, commenting

that every donor makes a huge impact not only on that one recipient, but also on the many people around them.

As well as updates from Lisa Burnapp of NHSBT (see page 3) and Lynsey Williams re the BOUnD study (see page 4), there was a talk from Carol Jennings about her interesting role as an Independent Assessor with HTA - and a moving yet amusing talk from kidney recipient Richard who is an Advocate for the charity *Live Life Give Life*, which aims to encourage more people to register as organ donors and raise awareness and public acceptance of organ donation.

Trustee Paul Gibbs, who is a vascular and renal transplant surgeon in Portsmouth Hospitals NHS Trust, pointed out that 600 altruistic living kidney donations will save the NHS £12-15m per year over the cost of dialysis for every year the kidney works after the first year when the costs are comparable. He posed a 'moral dilemma' for participants to discuss a real life situation involving a chain which caused the surgical team to think deep about what their actions should be.

BOUnD study group update

In the UK, more than 550 people have donated a kidney to someone they did not know (unspecified donation or non-directed altruistic donation).

Whilst many renal failure patients have been helped by these donations, little is known about the experiences of the donors, the reason why they chose to donate or the obstacles they may have faced during their donation process. Furthermore, the transplant community needs to find out if anything further can be done to understand why some potential unspecified donors could not go ahead to give a kidney.

The BOUnD Study is a national research project aiming to understand the experiences, emotional and physical outcomes of those that have engaged with the UK's national unspecified donor programme. It is funded by the National Institute of Health Research and aims to investigate donors' as well as transplant professionals' viewpoints.

If you are considering being an unspecified donor or are currently in the donation process, ask your transplant co-ordinator to refer you to the BOUnD team. If you are a transplant co-ordinator please get in touch with us at rebecca.gare@gstt.nhs.uk or call us on 07939 207381 once you have obtained donor approval.

Tell us your views and help future unspecified ("altruistic") donors and their healthcare teams reduce the burden of kidney failure.

Contact us

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