

Give a Kidney – one's enough Annual General Meeting & Conference

Saturday 25th March 2017

CZWG Architects, 17 Bowling Green Lane, London EC1R 0QB

Join us for the following:

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| 09.30am | Coffee/tea and biscuits |
| 10.00am | Welcome and introduction, followed by reports from the Chair, Executive Officer and Treasurer, and Confirmation of Trustees |
| 11.00am | Lisa Burnapp, NHSBT: Where we are now |
| 11.30am | BOUnD study |
| 12.00noon | Chains, choices & possible obstacles |
| 12.15pm | Discussion, followed by lunch and photocall |
| 1.45pm | Jan Shorrock: media update |
| 2.05pm | A recipient's perspective |
| 2.25pm | Paul Gibbs: A moral dilemma |
| 3.30pm | 3.30pm Summary and close |

Afterwards at The Bowler, 32 Bowling Green Lane, EC1

We look forward to welcoming John Fletcher and Gill Owens as new Trustees, bringing the total to eight Trustees. There will not be a contested election this year.

If you haven't already done so, you can register to attend via Evenbrite or contact giveakidneyoffice@gmail.com

Our appeal to you

In the last newsletter I noted the amazing progress Give a Kidney has made and is making in raising awareness, influencing change and supporting donors past and future. This has only been made possible by the paid (and considerable unpaid) work of the Give a Kidney team and the financial support of our members and supporters. We are extremely grateful for all your fundraising efforts and financial contributions over the years - indeed, without you we would not have succeeded at all.

Until recently this financial support has been sufficient to make the enormous impact we set out to achieve. Our success has opened many new doors of opportunity but this inevitably requires more resources and incurs additional cost, and we are now eating into our reserves. Consequently, the work we still wish to do is severely constrained.

We have been looking at various ways to increase the fundraising income of the charity. We have approached trusts and foundations with some success and we are in discussion with potential corporate sponsors.

Could you help?

Would you be in a position to make Give a Kidney a regular cause to support by setting up a monthly standing order of an amount consistent with your own circumstances and priorities? Churlish though it seems to ask you to stretch your generosity further, I hope you find yourself able to do so, because a regular income would help us to plan our spending more effectively and support the many programmes that we have started and need to develop further.

Bob Wiggins, Chair

Donating a kidney: where to go for advice

Get in touch with the Living Donor Co-ordinator Nursing Team in your closest kidney transplant centre for an initial chat - you can find contact details on our website. NHS Blood and Transplant has a useful leaflet: 'Could I be a Living Donor?' and information on living kidney donation on their website. Or you can 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-shaped love for Valentines

February saw the launch of NHSBT's new campaign around living donation, aptly named 'Kidney-shaped Love', timed for the run up to Valentine's Day. Using the hashtag #ShareYourSpare, the campaign predominantly focused on social media activity with some supplementary PR activity.

Give a Kidney were very pleased to have supported NHSBT in this campaign which marked their first dedicated living donation campaign. A separate campaign to promote living kidney donation in Scotland ran simultaneously.

Hits to the living donation pages on the NHSBT website rose by more than 600% in the two weeks the campaign ran. You can watch the quirky campaign on YouTube (search for 'kidney-shaped love').



News from Give a Kidney Scotland

Give a Kidney Scotland's group meeting held on 16th January 2017 in Edinburgh was well attended, with an excellent presentation by Jen Lumsdaine of the Royal Infirmary of Edinburgh (RIE) who has been seconded to work throughout Scotland on promoting altruistic donations and improving information for recipients. She summarised the history of altruistic kidney donation in Scotland and talked about the launch of the new website *Tell me about Living Donation*, a one-stop site with everything you need to know about donating in Scotland.

A press campaign planned to raise awareness ran for four weeks, with new leaflets. RIE would like to work with Give a Kidney Scotland to help promote and inform about living donation, highlighting local stories.

Other activities

A living kidney donation seminar was held in Glasgow's Queen Elizabeth University Hospital with talks by donors and a recipient. The event provided an opportunity to chat to some prospective donors and meet one of our West Coast members, Rodger Webster. Also at the event was Stevie Blom, a recipient who has set up a new charity called *Return to Life*, to support kidney transplantees and prospective donors before and after transplant operations by providing

things such as mentoring relationships, opportunities for physical exercise and activities, counselling and preparedness for forthcoming life changes. Give a Kidney Scotland hopes to be able to help *Return to Life*, particularly in 'buddying' prospective living donors with people who have been through the process.

Proposed BBC documentary

Fiona Hill, a producer for the BBC Science Unit, is making a documentary about altruistic living organ donation for BBC Radio 4. She is interested to hear from people who have used social media - or are currently planning to launch a campaign - to appeal for an organ donor, or people who have donated, or are considering donating, an organ to a stranger inspired by appeals they have seen on social media. Conversations will be confidential and contributors don't have to take part in the programme. You can email her at fiona.hill@bbc.co.uk but it's advisable to talk to Dorothy Fenwick of Give a Kidney Scotland first (dorothy@djfenwick.co.uk) and also Di Franks, whom many of you will know through her excellent blog *Living Kidney Donation* who passed on the news of the BBC initiative.

Draft Buddy Guidelines

Give a Kidney Scotland are producing draft Buddy Guidelines - yet to be finalised. The aim is to achieve a consistent, measured approach to buddying, with an eye on protection for both parties.

John Fletcher / Colin McLachlan



Richard de Soldenhoff, pictured above, was back climbing Munros just weeks after his donation. He has been active in promoting living kidney donations through his local newspaper, *The Broughton Spurtle*, and is currently corresponding with the BBC regarding their planned Radio 4 documentary.

Transplant Games in Scotland

Give a Kidney Scotland are going to have a stand at The Transplant Games just south of Glasgow from 27th - 30th July and would welcome all kidney donors and recipients - some of whom will be competing.

Note

If you live in Scotland and would like to become a member of Give a Kidney Scotland, or to contact them for any other reason, write to secretary@giveakidneyscotland.org

World Kidney Day

World Kidney Day on Thursday 9th March was marked with events up and down the country aimed at raising global awareness of kidney disease and drawing public attention to the importance of kidney health. The theme this year was '**Kidney Disease and Obesity**'. Some Give a Kidney supporters had stands, including a team at the Royal Free and, pictured here, Paul Dixon in Royal Liverpool Hospital.



Give a Kidney receives £500 from Heawene Brim

Give a Kidney were delighted to receive a cheque for £500 a few days ago. Non-directed donor Susan Greig explains the gift:

"My husband Alan works on an offshore installation called Heawene Brim based in the North Sea. Throughout the year the crew runs raffles, lotteries etc and the oil company donates money towards a welfare fund which is split equally between buying stuff for the crew's welfare and nominated charities".

"Alan nominated Give a Kidney, telling them the story of my donation and the difference it has made to Megan's life (my young recipient). He explained



Jan Shorrock receives cheque from Alan and Susan Greig

the purpose of the charity and its aim to raise awareness of living kidney donation. The welfare committee agreed it was a worthwhile charity and very generously donated £500!"

"It's been a real honour for me to have been given this cheque to give the charity."

NHSBT Highlights

Since my last update, there are a few highlights worthy of mention. Undoubtedly, the 'Valentine's Campaign' is one, which you will read more about from Jan. The campaign was aimed at anyone who might consider donation—family members, friends and, of course, non-directed donors. As the first dedicated campaign for living donation, this was a milestone for NHSBT and the support and collaboration from GAK was instrumental and, as always, much appreciated. NHSBT was a hive of industry in preparation including updated website information with case study videos, production and distribution of 100 pop-up banners to transplant centres and their referring hospitals across England, Wales and Northern Ireland and collaboration with colleagues in Scotland to align the parallel campaigns. Initial website statistics showed a significant increase in the number of people visiting the NHSBT living donation pages, downloading information and spending several minutes per visit. Very soon we will be launching an on-line 'Expression of Interest' form on the NHSBT website for non-directed donation. Using the form, people will be able to register their interest as a donor and their contact

details will be sent directly to the living donor coordinator team in the transplant centre of their choice. They will receive an acknowledgement confirming receipt and a timeframe within which they should expect to hear from the team. This has been welcomed by donors and coordinators who will all benefit from a more streamlined referral process.

I am delighted that information about non-directed donation is now available in 10 static blood donation centres across England. This is a pilot, which will be rolled out to other centres once we have assessed the uptake and response. I am grateful to my nursing colleagues in the blood donation service who have helped me to introduce this – I know that it is long-awaited by the charity.

On a final note, you may have noticed from the statistics on the GAK website that last November saw 18 non-directed donations- an all time high and the same month in which living donation activity peaked at 113 donations. Activity inevitably fluctuates from month to month but it is always good to celebrate success! Thank you to all of you for your support and I look forward to seeing many of you at the AGM.

*Lisa Burnapp
Lead Nurse - Living Donation*



GIVE A KIDNEY'S 10TH ANNIVERSARY IS APPROACHING



Following the success of the media campaign around the 500th donation last year (thanks to all who participated), our next big milestone will take place this Summer when we'll be celebrating the 10th anniversary of the first non-directed kidney donation in the UK.

We're fortunate to have the support of the very first UK non-directed donor, Kay Mason, who left us all her footprints to follow in and helped to open up a new source of transplant opportunities for those in need - it's a cause for celebration indeed.

We'll be working closely with the unit involved, the surgeon who conducted the first donor operation of this type and hope to get some good media coverage around this time. Over the coming months and years, we're planning to run a specific local media campaign to celebrate the 10th anniversary of each city's first non-directed donation. Some of our members will be the first donor in each unit - if you know that you are and would like to be involved, please do let us know. We hope to find other ways locally to include local members, so more details will follow soon.

More Top Tips for donors

Marsha Eastwood became an altruistic donor last year. She comments that the best piece of advice she got before her operation was from her niece, who had undergone two major heart surgeries just a few months before:

- Don't set timescales or deadlines post op'. If you don't meet them you'll get frustrated and feel you aren't doing as well as you should.
- Listen to your body - don't over-do it if you are feeling you're having a good day: it'll only set you back.
- Do everything the hospital tells you to do to the letter and you will recover better.

Marsha found the only unexpected hardship in hospital was a dry mouth, which coupled with a lack of appetite meant she didn't eat for four days. A tube of gel which acts like saliva and some sponge lollipop sticks to rub around her mouth helped a great deal.

Give a Kidney is pleased to be working in partnership with NHSBT and other organ donation charities on a number of initiatives. In addition to collaborating on the 'Kidney Shaped Love' campaign, Give a Kidney has actively supported the following recent NHSBT activity:

- ◇ a new suite of information materials around living donation which are now printed and available online
- ◇ the publication of a leaflet specifically around non-directed donation which is now being piloted in ten static blood donation centres around the country, with a plan to distribute to more centres in the future
- ◇ the production of 100 banners promoting living kidney donation which will be used by transplant centres and their referring hospitals across England, Wales and Northern Ireland
- ◇ a number of short films around living donation (which some of our members have participated in) which are filmed and are now being edited and will be available this Spring.

Give a Kidney is also supporting the introduction of a new online facility on the NHS Blood and Transplant website to allow people to register their interest in becoming a non-directed donor and to contact their local transplant unit online. In the meantime, people can find out about how to become a living donor at: www.organdonation.nhs.uk/about-donation/living-donation/

Cryogenics breakthrough gives hope for transplant patients

Scientists have succeeded in cryogenically freezing and rewarming sections of heart tissue for the first time, in an advance that could pave the way for organs to be stored for months or years.

If the technique scales up to work for entire organs - and scientists predict it will - it could save the lives of thousands who die each year waiting for transplants.

The work is being hailed as a major development in the field of cryopreservation as it marks the first time that scientists have been able to rapidly re-warm large tissue samples without them shattering, cracking or turning to a pulp. The US team overcame this challenge by infusing the tissue with magnetic nanoparticles, which could be excited in a magnetic field, generating a rapid and uniform burst of heat.

Currently, donor organs such as

hearts, livers and kidneys must be transplanted within hours because the cells begin to die as soon as the organs are cut off from a blood supply. As a result, 60% of the hearts and lungs donated for transplantation are discarded each year, because these tissues cannot be kept on ice for longer than four hours.

Recent estimates suggest that if only half of unused organs were successfully transplanted, transplant waiting lists could be eliminated within two to three years. The latest paper has been hailed as a significant step towards this goal.

Mehmet Toner, a professor of bioengineering who is working on cryopreservation at Harvard Medical School, said: "It's a major breakthrough. It's going to catalyse a lot of people to try this in their laboratories. I'm impressed."

The Guardian, 2 March 2017

Tracey's wish to save as many lives as she can

Tracey Jolliffe from Fife in Scotland is an extraordinary woman, giving away her body bit by bit. She started on her selfless path when she enrolled as a blood donor at 18 (she has since contributed 80 pints to the national blood bank), and saw a notice about going on the stem cell register which helps treat patients dying from leukaemia.

In her late twenties she donated eggs to three couples to help them have babies.

"Giving childless couples the chance to become parents has given me immense joy" she says. "If you can help others safely without damaging your own body, then you should."

Tracey continued her mission to help others by donating one of her kidneys in 2012. She is one of the founding members of Give a Kidney UK.

"I read a newspaper story about saving a stranger's life through altruistic donation. So I approached my doctor and went through the process of a thorough medical before I was pronounced fit to save a kidney patient. I only wish others would consider this. I am still fit and healthy and so is the person I saved, as far as I know."

She is now considering donating a



part of her liver to save a dying patient.

"This is a more complicated procedure than having a kidney removed but it's very possible and I'm not putting my life at risk.

Tracey's father has a form of Parkinson's disease, which prompted her to volunteer to donate her brain for research after she dies, to help researchers look for differences between those with and without the disease.

"I wanted to donate my entire body, but donating a kidney means I am not 'complete' and universities prefer whole bodies to teach medical students."

"The feeling of saving a life is fantastic," said Tracey during a recent interview for The Sunday Post. "I am not at all religious," she insists. "My motivation doesn't come from a belief that I am earning a place in heaven by doing good works. I firmly believe we should all do what we can to make life as happy as possible for others."

Abridged from The Sunday Post, Scotland. Tracey Jolliffe has also appeared on BBC One's 'Victoria Derbyshire' show, and her story features in 'Closer' magazine, BBC Radio Scotland and Kingdom FM.

Brandenburg choral concert, 16th November 2016 - almost £1,000 raised



The charity was fortunate to benefit from the proceeds (half of any tickets sold through the charity, plus any donations) of a choral concert on Wednesday 16th November 2016, part of the Brandenburg Choral Festival of London. Worcester College Oxford Chapel Choir sang Fauré Requiem in the beautiful Queen's Chapel of the Savoy.

Before the concert, there was a reception to celebrate the charity's 5th birthday. This also presented an opportunity for members to meet up with others and to recognise the progress made in raising awareness of non-directed altruistic kidney donation.

During the interval, guests enjoyed a talk about the fascinating venue. The Savoy Chapel was founded in the Middle Ages as part of the main church of the Savoy Palace (later the Savoy Hospital). Most of this was demolished in the early nineteenth century for redevelopment and to allow the construction of the approach road to the new Waterloo Bridge. All that survives today is the Chapel of St John the Baptist, now known as The Queen's Chapel of the Savoy.

Our concert quickly sold out and proceeds, which included a collection at the door, came to almost £1,000. We are grateful to Brandenburg Choral Festival of London, who we hope to partner with again in Autumn this year, to everyone who attended and to member Celia Kent for recommending us as a charity partner.

Contact us

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