

## Annual General Meeting & Conference

Saturday 24th March 2018, 9.30am - 3.30pm

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

## Celebrating ten years of non-directed kidney donations

**10  
years**

This Summer we celebrated the 10th anniversary of the UK's first non-directed kidney donation by Kay Mason and media coverage included Sky News, Daily Mirror, BBC London and, the icing on the cake, BBC Breakfast - with Kay joining the team via a live link from home, and Give a Kidney's Jan Shorrocks joining the Breakfast sofa team in their Media City studio in Salford.

We are aware that this resulted in at least two donors

coming forward for assessment to transplant units but there may be many more similarly inspired. It certainly raised awareness of non-directed kidney donation with several million people.

Kay was the very first person in the UK - in the summer of 2007 - to donate a kidney to somebody she didn't know and had to fight long and hard for the right to do so. Her decision goes back to 2001 when she found out you did not need to be a blood relative to donate and that in fact friends could do so. But when the former palliative care nurse made the life-changing decision to help a stranger, she found the doors were, at that time, firmly closed.

"I can't remember a precipitating factor, it just seemed to make no sense to me that I wasn't able to donate my kidney unless I knew the person," said Kay. "To be honest it seemed I faced a real struggle everywhere I turned back then. There had been a 'kidneys for sale' scandal and if you weren't related you



*"To me a stranger was only a friend or acquaintance I hadn't met."*

had to prove you knew the person. The thinking was you had to be mad to want to give a kidney to a stranger and if you were mad you couldn't be allowed to give. But I was perfectly sane. My kidneys were healthy, I was already 60 and I didn't have kidney disease so I reckoned I could survive comfortably with just the one. To me a stranger was only a friend or acquaintance I hadn't met."

With the help of supportive clinicians, Kay was finally able to feed into a consultation process which helped pass new legislation enabling her to donate. The Human Tissue Act 2004 came into force in September 2006 and Kay's surgery was carried out the following

summer at the Royal Free Hospital in London by Mr Peter Veitch.

Since Kay's groundbreaking surgery more than 600 other people in the UK have been able to donate their kidneys to people they do not know.

Bob Wiggins, Chair of Give a Kidney, said: "Kay's fight was instrumental in helping change government policy. What she began ten years ago has led to

hundreds of kidney patients being given opportunities for transplants they may not otherwise have had.

"Times have changed enormously over the last ten years and now every transplant unit in the country has a programme for non-directed kidney donors.

"However, there are still more than 5,000 people in need of a kidney in the UK and around 250 people die each year because there are not enough organs available from deceased donors, so there is still a need for yet more people to consider donating in this way. We remain grateful to Kay and the team at the Royal Free Hospital for taking this hugely significant step in the Summer of 2007.

### Donating a kidney: first steps

Have a look at the "How do I go about donating a kidney?" page on our website [giveakidney.org](http://giveakidney.org) - and if you have any questions, email [giveakidneyoffice@gmail.com](mailto:giveakidneyoffice@gmail.com) and we'll do our best to help.

# Donors, recipients and supporters making a difference

## Alice Green runs back to back marathon to raise money before donating her kidney

To celebrate my recent kidney donation, I decided to run a 'double marathon' in April in aid of GSTT Kidney Patients Association. It involved running the London marathon route in reverse at 3am, followed by running it forwards with the other 40,000 people (52 miles!) and the final total I raised and was £2,144.95 with Gift Aid. I'm a keen runner and plan to continue running marathons and ultra marathons in the future - fingers crossed that will be possible!

Total distance travelled: 94.25 kilometres.  
Calories burned: 7595.  
Time awake: 21 hours.  
Total running time: 10 hours, 8 minutes.  
Funds raised for GSTT Kidney Patients' Association: £1741 (£2055 with gift aid).



### Volunteer bookkeeper wanted for approx two hours per week

The role would involve liaising with our Treasurer and Administrator, logging membership fees and other donations. You'll 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](mailto:giveakidneyoffice@gmail.com)

We are very grateful to all those who support the charity with a financial contribution. As we receive no government funding, we rely on this support in order to continue the work that we do: raising awareness of non-directed (altruistic) living kidney donation and supporting those who are interested in donating in this way.

A considerable amount of unpaid work is also undertaken to keep the charity running and that helps keep costs to a minimum. Despite its small size, the Trustees are proud of the impact the charity has had and the progress that has been made in altruistic donor numbers since it was set up six years ago.

We wanted to let you know that we recently registered with BT MyDonate (see [mydonate.bt.com](http://mydonate.bt.com)) which allows donors to set up a monthly donation, as an alternative to a Standing Order. Gift Aid claimed on the charity's behalf further boosts donations. You can also set up a fundraising page on the site - as you can with JustGiving -

so do bear that in mind if you decide to take on a challenge or do some fundraising as part of your New Year's resolutions!

Thank you in advance for your generous support.

### PLEASE NOTE...

If you are running awareness events, there is a range of printed and promotional materials available to support you, including leaflets about living donation and non-directed donation, A5 flyers and pop-up banners. Jan Shorrocks has a full list of these, which are available on request from [leaflets@nhsbt.nhs.uk](mailto:leaflets@nhsbt.nhs.uk) - plus Give a Kidney's own material.

In the next issue, read how non-directed kidney donor Paul Dixon has single-handedly raised £1000 for Give Kidney - just by talking. Be inspired!

## Hugh and Tom raise £467 for Give a Kidney with a cycle challenge

When he decided to take on a cycle challenge with his 9 year old son, Tom (a mad keen cyclist), Hugh Jackson was on the national transplant list, waiting for the call for a kidney transplant.

For several consecutive years, Hugh had taken part in the Smethwick Challenge, a three-day cycle from London to Birmingham in May. By 2017, his kidney disease had progressed and he was on dialysis, so was unable to take part in the whole ride. However, he did meet up with the others and was able to cycle most of the final day of the ride, with Tom (pictured together, right).

At the time, Hugh's mother was undergoing tests to determine whether she could donate a healthy kidney to him. Finally, the good news arrived that she



was a suitable match. After the operation in September this year, Hugh (with mum, left) commented that "the immediate feeling of well-being from the moment of waking up from the operation is remarkable".

You can hear him being told that he is to be listed for a kidney transplant on Radio 4's File on Four programme 'The Organ Beauty Pageant' on Tuesday 2nd May at 8pm <http://www.bbc.co.uk/programmes/b08nq6fh>

We are very grateful to Hugh, Tom and everyone who contributed to their fundraising.



Over the last year or two we have been developing more information and resources for people who might be interested in living donation. If you haven't come across them already, the 'Let's talk about living donor kidney transplantation.....' films, sponsored by NHSBT and filmed in collaboration with 'Transplant TV', were released in the summer and can be accessed through our webpage at <https://www.organdonation.nhs.uk/about-donation/living-donation/>. The series includes a core film covering all aspects of living kidney donation, described through the experiences of donors, recipients and professionals and a suite of shorter films, each discussing a single topic in more depth. You will see some familiar faces from the charity - many thanks to everyone involved in this project from behind the scenes and in front of the camera - the more we talk about living donation, the more difference we make.

Over the next six months, we will be adding further educational materials to the NHSBT website, including factsheets to provide detailed answers to frequently asked questions. Jan Shorrock is leading on this with clinicians from the LDKT 2020 strategy implementation group. Following the pilot in blood donation centres, information about non-directed donation will be available in all blood donation centres by

the end of this year; something that I know is dear to your hearts.

The January deadline for all non-directed donors to donate into a chain (provided that there is no recipient of higher priority on the national transplant list) is almost here. We know that this change will benefit many more patients waiting for a transplant and we hope that people considering donation will be inspired to donate by seeing the opportunities created by their single donation. NHSBT has been working with clinical colleagues across the UK to ensure that the transition is as smooth as possible, particularly for donors entering the programme. We would welcome your support in embedding this initiative and in your discussions with people who approach the charity about donation so that they are aware of how the scheme works in principle.

NHSBT are very appreciative of the collaboration with 'Give a Kidney' and thank you all for your continued support, collectively and individually. As always, please contact me at [lisa.burnapp@nhsbt.nhs.uk](mailto:lisa.burnapp@nhsbt.nhs.uk) if you have any questions or queries about anything in this update.

In the meantime, a very Merry Christmas and Happy New Year to you all!



*Lisa Burnapp  
Lead Nurse - Living Donation  
NHS Blood and Transplant*

## Psychology in the Pub

Although Plymouth has a relatively small transplant unit, it has been a front runner when it comes to non-directed donation. The psychology department at the university has also been involved and is actively researching the area. They participate in the BOUnD study and some of you will probably have been interviewed by them.

They took advantage of a British Psychological Society initiative called 'Psychology In The Pub' to help promote understanding of psychological research and, fortified by the provisions of the venue, the Plymouth department held a lively meeting on 21st September with academics and donors as well as an audience of students and the public. It was an opportunity to learn about the research and some individual experiences.

While donation itself is not yet as common place as we would wish, there is clearly a lot of interest. Seeing that donors are ordinary people combined with more awareness about the possibilities should remove some of the barriers and encourage others to consider donating themselves.

*Paul van den Bosch,  
Trustee, Give a Kidney*

## European Society for Organ Transplantation 2017

### Conference in Barcelona

Last year I gave a presentation at the European Organ Donation Conference in Rome at which I explained how UK numbers of non-directed living kidney donations (NDLKD) had increased dramatically since Give a Kidney started and discussed the potential value of an NGO separate from official government control. Many countries in Europe do not yet allow non-directed living kidney donation, and I hoped that publicising UK activity might encourage other countries to do likewise.

A leading light in European kidney transplantation liked this and invited me to talk on pushing for more non-directed living kidney donations at the European Society for Organ Transplantation in Barcelona this September. There were 3,000 people

attending from 90 countries. Most presentations were about the technology of organ transplantation, but about 40 members were interested in my session. I explained the UK's excellent system of assessing donors, selection of recipients and of the transplant and follow-up. To date about 600 UK adults had given a kidney to a stranger - not enough and not still increasing, but a wonderful example of altruism in action. Give a Kidney and I believe passionately that we should continue to inform and assist people to give a kidney to a stranger.

### Raising the issue of incentives

I then broached a different topic, which could reduce unnecessary deaths and years of suffering on dialysis: if, despite Give a Kidney's efforts, there are still

not enough kidneys available to meet demand, what else can be done to increase the number of non-directed living kidney donations? A Dutch study suggests people would be more likely to donate if there were incentives or inducements. The subject has been debated over the last 30 years but has always been turned down for, to many people, quite invalid reasons. According to professors of medical ethics there is no ethical reason not to offer a reward for donating an organ but the idea of inducements is still not accepted by NHSBT and is outside the remit of Give a Kidney. Yet with the desperate need for more kidneys there is a need for the issue to be debated.

*Chris Burns-Cox,  
Trustee, Give a Kidney*

## HEALTH RISK OF LIVING KIDNEY DONATION

The risk of dying as a result of kidney donation is

 1 : 3000

- approximately the same as having your appendix removed.



Humans can live a full and healthy life with only one kidney.



- in fact some people are only born with one and may never know!

The risk of a donor having kidney failure later in life is very small as donors are thoroughly screened in advance.



However, if it were to happen, living donors are offered additional prioritisation on the transplant waiting list within certain criteria.

SOURCE: NHS BLOOD AND TRANSPLANT

‘What we think, or what we know or what we believe is, in the end of little consequence, the only consequence is what we do.’

**John Ruskin**

## US star Selena Gomez receives kidney transplant

Twenty-five year old Texas born singer and actress Selena Gomez, who has lupus, received a kidney transplant from her friend, TV actor Francia Raisa of *The Secret Life of the American Teenager*.

The singer, who has almost 130 million followers on Instagram (the second-most followed user on that platform), revealed her lupus diagnosis in 2015 and took a break from her career last year to deal with anxiety, panic attacks and depression stemming from her battle with the disease.

Her Instagram post includes a picture of herself and Raisa holding hands while lying side-by-side in hospital beds and another photo of a scar on Gomez's abdomen. Gomez wrote "there aren't words to describe" how she can thank Raisa, who she says gave "the ultimate gift and sacrifice by donating her kidney."

Lupus is an autoimmune disease, where the body mistakenly attacks its own tissues, sometimes including the kidneys. One healthy kidney is all the body needs, so a single kidney transplant can resolve the problem, said Dr David Klassen, chief medical officer for the United Network for Organ Sharing, which runs the United States' transplant system.

"Lupus tends to be a disease of younger women, and younger people tend to do better with transplants than older patients, so the expectation

is she would do quite well," he said of Gomez. Lupus also tends not to come back after the operation as the drugs that prevent kidney rejection are also very good for treating lupus, the underlying disease.

*Extracted from The Guardian, 14 September 2017*

## News from Give a Kidney Scotland



Norman Thornton is planning to write a book about the experience of donors and recipients. He also plans to interview family members regarding their attitudes to the donation. If you are interested in being part of his project, please email Colin McLachlan at [secretary@giveakidneyscotland.org](mailto:secretary@giveakidneyscotland.org) and he will pass your message on to Norman.

Pictured above, members of Give a Kidney Scotland Grant Thomson and Marsha Eastwood, who both ran in the Donor Run at the British Transplant Games 2017 (Grant achieved second place in his class). Along with Colin McLachlan, they manned a Give a Kidney Scotland stand at the Games which proved quite a draw. They met many interesting people, made some sales and spread the word about non-directed kidney donation - with at least one person expressing a serious interest in donating.

Also taking part in the Games was Alan Wallet pictured here (left) with two donors from England: former Queens Guard Lee Fenlon and Sue Gianstefani. The donor 4 x 50m freestyle relay swimming competition was held in the Sir Matt Busby Sports Centre in Bellshill. One swimmer from the England / Scotland team didn't turn up, but since the Northern Ireland team had a full four-person squad, Alan had to swim twice. As a result he was awarded two medals!



Marsha Eastwood was thrilled recently to receive a letter from Stephen Kerr, MP for Stirling who had read her newspaper article and wrote:

*"I read about your charitable activities in the Stirling Observer on Wednesday and I thought I would write you a letter to offer my congratulations on your work. The work of Give A Kidney has helped a great many people and your work has drawn attention to the number of people waiting on transplants across the UK. Please accept my congratulations and best wishes for the future. What you are doing and have done is exceptionally inspiring".*

### Contact us

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