

Welcome to our Spring / Summer newsletter. I hope you had a very enjoyable long weekend last month and are able to make the most of the fine weather as and when it presents itself. You may be aware that our Charity's vision is 'no waiting for a transplant for want of a kidney'. Everything we do is with that in mind. Specifically, we focus on three areas relating to non-directed (altruistic) living donation: raising awareness, supporting donors (before and after) and influencing change.



Much of our unseen work involves influencing change through collaboration with other charities, kidney patient forums, NHS Blood and Transplant, NHS transplant centres, and UK/European medical societies dedicated to organ transplantation such as British Transplantation Society (BTS) and European Society of Organ Transplantation (ESOT). The profile of non-directed living donation within all these organisations has risen dramatically in recent years due to in large part to the efforts of Give a Kidney with the enormous support and assistance of one of our biggest advocates, Lisa Burnapp, Associate Director NHSBT - Living Donation and Transplantation.

Together we have worked on numerous initiatives that are making a real impact on many aspects of living kidney donation. In the autumn of last year, I was invited to join the NHS Organ Utilisation Group (OUG), tasked by the Medical Director of the NHS to review the current organ transplantation system and deliver recommendations on how to maximise the potential for organ transplantation in the UK. I represented living donors on the data and systems subgroup which offered an opportunity to contribute and share ideas about how the living donor experience could be enhanced through ready access to information and data. The whole of the OUG recommendations to Ministers, if adopted, has the potential to be a real game changer in increasing the number and quality of organ transplants.

Another game changer over the past number of years has been the UK Living Sharing Scheme (UKLSS) which potentially produces three living kidney transplants for each non-directed living donor. This is a very complicated process of matching donors and co-ordinating the transplants. A few weeks ago, I was delighted to attend an NHSBT Living Donation Project Away Day to kick off a project to expand the computerisation of the Sharing Scheme. This will have a significant impact on the continued success of the Sharing Scheme in terms of numbers of transplants, whilst at the same time reducing the burden on transplant staff who are already stretched for time and resources.

These are just two examples of my recent collaboration to

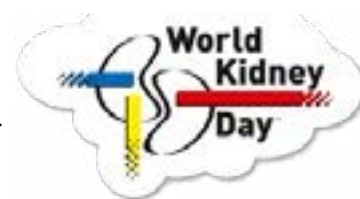
influence positive change. Our Executive Officer, Jan Shorrocks, is directly involved with many other initiatives with partner organisations. She presented a non-directed living donor perspective on the HESPARIS course once again this April. This course is an ESOT course for new clinicians coming into transplantation across Europe. This is very significant as most European countries don't enjoy the same level of non-directed donation as the UK and in fact it is not allowed in some countries, so the opportunity to influence practice not only in the UK but across Europe is significant. She also presented a similar session at the new Living Donor Co-ordinator course for the first time this spring and it will be a regular feature on that course going forwards.

Earlier in the year Jan also helped judge applications made to the Living Kidney Transplant Scheme, part of the wider Community Investment Scheme. You can read more about this scheme on page 2.

It is through these efforts that Give a Kidney is held in such high regard and with credibility throughout the transplant community.

Bob Wiggins, Chair of Trustees

In the media



Since our last newsletter there have been a number of interesting pieces in the media: BBC Scotland

featured non-directed donors and Give a Kidney supporters Tracey Joliffe and Maureen Jack on their Sunday Morning programme who discussed, in depth, their decisions to donate.

BBC Ideas also presented a thought-provoking piece, featuring transplant surgeon Frank Dor, asking the question 'Should human kidneys be bought and sold?' The link is still available here: <https://bbc.in/3lVGO1B> and is well worth a listen.

In March, we were pleased to work closely with the Press Team at NHS Blood and Transplant again around publicity for World Kidney Day, focusing on living donation. This resulted in some great coverage. Our Executive Officer, Jan, was a spokesperson for the campaign and was interviewed on ITV regional television news and a selection of regional BBC radio stations, with a number of non-directed donors also being featured.

We are now looking ahead to the 1000th non-directed donation which we hope will be coming up in the not-too-distant future, and beginning to make plans for how we might use this as a hook for further publicity – more details coming soon!

Working with NHSBT

As mentioned above, our Executive Officer Jan Shorrock was recently one of the judges of applications to the first round of the Living Kidney Transplant Scheme which is part of the wider NHSBT Community Investment Scheme.

The Living Kidney Transplant Scheme aims to:

- Increase awareness and relevance of living donation across Black and Asian communities
- Increase the diversity of prospective living donors
- Increase the number of non-directed living donors
- Enable more patients to receive the best matched kidney.

The scheme funds community and faith and beliefs organisations to positively

engage Black, Asian, Mixed Race and minority ethnic communities in living kidney donation.



We know that trusted local organisations can be successful at achieving these goals, due to their specialist knowledge, understanding and footprint in the community.

Funded projects drive awareness of living donation, address misinformation and barriers, share information and drive behaviour change, therefore increasing support for living donation.

After a three-stage application process

seven successful organisations were awarded funding and they will work with NHSBT to deliver their projects during 2022 and into 2023. They are:

- [African Caribbean Leukaemia Trust \(ACLT\)](#)
- [City Sikhs Foundation](#)
- [Community Barnet](#)
- [JHOD and Royal Free](#)
- [Nishkam Healthcare Trust](#)
- [University of Leicester / Centre for Ethnic Health Research](#)
- [Vanik Council UK](#)

You can find out more about the scheme and this round of funding here:

<https://www.organdonation.nhs.uk/get-involved/news/funding-to-tackle-health-inequalities-and-promote-living-kidney-donation-amongst-black-asian-and-minority-ethnic-communities/>

Meet the team...

We recently advertised for new trustees for the charity and were truly delighted with the calibre of applications. After a very difficult decision making process we have recruited five new Steering Group members, who bring a mix of medical expertise and lived experience to our charity.



Edward Hibbert

Edward has worked for many years in IT, and now does IT work for the third sector. He is particularly interested in how technology can create virtual communities and since 2005, has been involved in Freegle, which helps people give away stuff they don't need to people who do. In 2018 he took this one step further by making a non-directed kidney donation.



Dr. Adnan Sharif

Consultant Nephrologist at the Queen Elizabeth Hospital Birmingham, Dr Sharif has an active research focus and he serves as board member for the UK Organ Donation and Transplant Research Network research stream, co-leading on the long-term outcomes theme. He is also Secretary of the non-Government Organization Doctors Against Forced Organ Harvesting (DAFOH) which campaigns against illegal and unethical organ procurement around the globe, which was nominated for the Nobel Peace Prize in 2016 and 2017, and received the Mother Teresa Memorial Award for Social Justice in 2019. He is on the Board of Trustees for Kidney Research UK and the Global Kidney Foundation, and sits on the British Transplantation Society Council representing Transplant Nephrology. Finally, he is a long-term member of the National BAME Transplantation Alliance that seeks to promote blood, stem cell and organ donation from minority ethnic groups in the UK, and has been involved in numerous campaigns regionally and nationally to raise awareness of organ donation in under-represented communities.

Caroline Basarab-Howarth



One of our new Trustees, Caroline has been a Living Donor Co-ordinator in Sheffield since 2005. She is a registered nurse with 23 years' renal experience. She recently initiated the "Daisy Chain" Thank You' cards for non-directed donors, that are now available nationally. Caroline feels "extremely privileged to be part of living donation and to work with such amazing donors".

Chris Luck



Chris is a project manager, with a background in strategy development, communications, and change. He works for a leading UK university planning and co-ordinating change initiatives. Chris donated a kidney to a friend in 2021 and relied on insights from Give a Kidney to make an informed decision. He's now passionate about enabling others to make the same informed decisions about donation.

Harry Hobson



Harry lives on a houseboat in Hammersmith. He has two children and enjoys mountain-biking, paddle-boarding, beekeeping and TV. He works for Neighbourly Lab, a non-profit think-tank about communities, and also does consulting and innovation work around technology and religion. He donated a kidney in 2020 to an unknown person and considers this to be one of the best things he's ever done.

Many thanks to those who joined us for [Ask the Experts – Living Kidney Donation](#), held on 29th January 2022 as part of the Winter Webinar series. The experts on the panel were Consultant Transplant Surgeon Frank Dor, living kidney donor and GP, Dr Paul van den Bosch, Consultant Transplant Nephrologist, Dr Adnan Sharif and Associate Director, Living Donation & Transplantation, NHS Blood and Transplant, Lisa Burnapp.



Ask the experts: living kidney donation



Mr Paul Gibbs, Clinical Director of the Transplant Programme, Queen Alexandra Hospital, Portsmouth



Dr Paul van den Bosch, living kidney donor and GP



Dr Adnan Sharif, Consultant Transplant Nephrologist, Queen Elizabeth Hospital, Birmingham



Lisa Burnapp, Associate Director, Living Donation & Transplantation, NHS Blood and Transplant

The second Webinar was held on Saturday 26th March, with Mr Prodomos Laftsidis, Consultant Transplant Surgeon at Portsmouth Hospitals University NHS Trust. He spoke on the subject of Robotic Surgery in Organ Donation and Transplantation, what procedures are involved and the benefits for living kidney donors and transplant recipients.

Mr Laftsidis was inspired

to work in the field of transplantation when his sister underwent a kidney and pancreas transplant in his native Greece, and he saw her quality of life improve so dramatically. He obtained his surgical training in Democritus University of Thrace, one of the three largest universities in Greece, before moving to the UK. You can watch his talk here but please note that the webinar includes filmed footage of surgical procedures. - <https://www.youtube.com/watch?v=ROojToQ1UHs>



Q & A

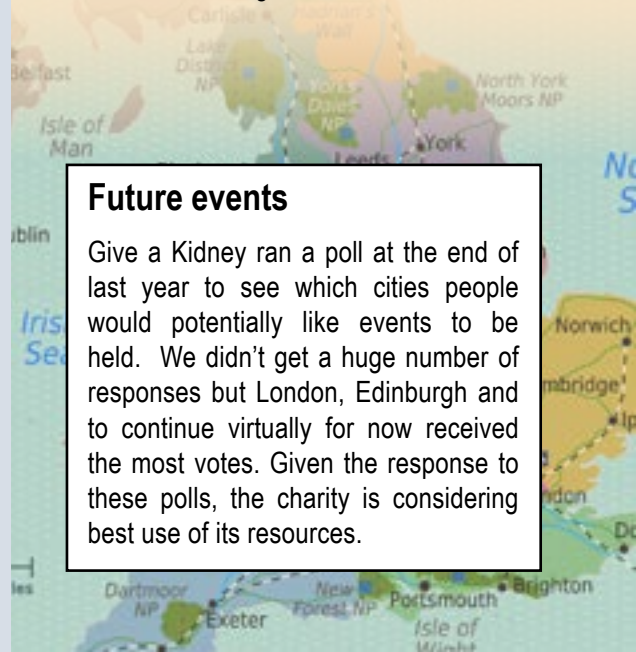


- 1 Will I have to refrain from playing certain sports if I donate a kidney?**
In the immediate recovery period you will be advised to avoid strenuous activity but once you have recovered you can lead a normal healthy life.
- 2 But what if I get injured whilst playing sport after donating a kidney?**
Losing a kidney through direct trauma is very uncommon, particularly whilst playing sports. With only one kidney you'd be at slightly higher risk of becoming dialysis dependent if you lost your remaining kidney but this risk is very small.
- 3 Will I be on lifelong medication after donating?**
No, you will need to take painkillers immediately after your surgery and you may also need to take antibiotics for a short period of time. However, you will not need any long-term medication as a result of kidney donation. It is kidney recipients who usually need to take immunosuppressant medications for the rest of their lives to prevent their body's immune system from attacking the new kidney.
- 4 Can kidney donors have successful pregnancies?**
Yes. Many women have had babies after donating a kidney without any impact on the pregnancy from the kidney donation. In general, women may choose to wait until they have completed their family before becoming a living donor. This is for practical as well as health reasons. Research in this area is limited but careful discussion and counselling about the potential risks are essential to avoid undue risk for any woman of child-bearing age who plans to donate. We recommend that all women who become pregnant after donating a kidney are seen by their care team regularly throughout their pregnancy, to check their blood pressure, kidney function and the developing baby's well-being.

Many thanks also to those who donated after the events. Don't forget to subscribe to our YouTube channel. Once we hit 100 subscribers, we can actually create our own channel in our name, and in future the more subscribers we get the better chance we have of monetising the channel to bring in much needed funds.

Future events

Give a Kidney ran a poll at the end of last year to see which cities people would potentially like events to be held. We didn't get a huge number of responses but London, Edinburgh and to continue virtually for now received the most votes. Given the response to these polls, the charity is considering best use of its resources.



Can you fundraise for us?

It costs around £1500 a month for Give a Kidney to carry out 'business as usual', which includes all the work influencing change and contributing to policy around living kidney donation, some of which our chair Bob Wiggins highlights above. Our regular supporters contribute around 20% of this for which we are truly grateful. If you would like to become a regular financial donor you can do so via [Just Giving here](#) - or please do get in touch and we will pass on our bank details in order for you to set up a standing order. However, in these difficult times as the cost of living increases and inflation rises there are other ways to support us.

Raffles and auctions

One of our supporters held a workplace raffle whilst working on a new feature film and raised a total of £500. The main raffle prize was a Fortnum and Mason's hamper kindly donated by the family of one of our founders Chris Burns-Cox who is sadly no longer with us. Huge thanks to the Burns-Cox family for this donation and to all the crew of Firebrand and the staff of Haddon Hall who bought tickets and made donations.

If you could hold a raffle or auction either at your workplace or club or group, during another event such as a fête or party, or for your customers, and think you could raise £500 or more, please get in touch with us as we may be able to support you with items for your raffle or auction. Last summer we were kindly donated a signed Arsenal shirt and a couple of other smaller items which we still have. We also never sold our afternoon tea with the stars of Downton Abbey so we may even be able to secure that for you!

Note that raffles require a gambling licence unless they are held in one of the circumstances mentioned above.

Nominate us to be your charity of the month or year

Cotham Parish Church in Bristol kindly selected Give a Kidney to be one of their charities of the month for March and raised the princely sum of £300. Our thanks to all the parishioners who donated and helped raise such a healthy sum towards our running costs.

Are you involved with a school, church, business, rotary club, women's institute that selects a charity each month or year to support? Could you consider nominating Give a Kidney? Not only would you be raising vital funds for us but also raising awareness of living kidney donation, our primary objective as a charity. We can supply posters, leaflets and other promotional materials to support you with your efforts.



A brand new, easy way to support us - introducing Nectar Donate

This means you can now donate any or all of your Nectar points to us! You will need to link your Nectar card to your Crowdfunder account. This does mean you will need to set up a Crowdfunder account to donate your points. Once you've done so, simply visit our dedicated page and when you get to the 'Payment method' screen, select 'Donate with Nectar'.

The best thing about [Nectar Donate](#) is that it won't cost you or us anything. Crowdfunder has generously waived platform fees for anyone donating their points. And don't forget, as you continue to shop at Sainsbury's, eBay, Esso, Argos, JustEat and many many others, all those points will soon add up!

Donate your
Nectar points

Your Nectar points can now
be used to support our charity



Give a Kidney T-shirts

We have a limited stock of 'Keep Calm and Give A Kidney' red t-shirts available to buy for £10 including postage and packing. They are available in the following sizes: small (approx. 36-38inches), medium (approx. 40 inches), large (approx. 43-44inches) and extra-large (approx. 46inches).



All monies raised over and above the cost of postage will support the Charity's work. Ongoing supporters and those of you who are raising money for us through a sponsored event are welcome to request either one of these t-shirts or one of our Give a Kidney t-shirts which will be sent to you free of charge.

Challenges

If you're thinking of doing a challenge whilst the weather is good – a swim, a run, a bike run, an abseil... don't forget we can help by providing sponsorship forms, t-shirts, and potentially some promotion via this newsletter and our social media.

