

#shareyourspare

In the last year we entered our second decade, dedicated to our vision of “no waiting for a transplant for want of a kidney”. In the first five years we built the foundations of the charity - raising awareness of non-directed living donation as something worthwhile of



consideration, providing confidence among the medical community that potential non-directed donors were ordinary people and, very importantly, establishing the credibility of the charity within the transplant community and the media as a force for good.

The next five years built on that foundation through the strengthening of partnerships, helping to drive progressive change in policies and practices to increase

the numbers of transplants coming from non-directed living donors, and improved support for donors before and after donation. The results, Covid aside, are impressive and the progress made would not have been possible without the incredible encouragement and help from all our supporters.

But we recognised that if we are to strive ever closer to our vision, we need to take the charity’s influence and activities to a new level. To this end, during the past year we have recruited a number of new enthusiastic Trustees with whom we are defining the next five years and defining what we hope to achieve. It will be as ambitious and demanding as the previous ten years, taking Give a Kidney to another level in

raising awareness, influencing change and supporting donors. Utilising existing and new technologies we will look to spread our message to a completely new level. This will not be easy – to do so we will require up to a five-fold increase in our annual income. Raising the necessary funds and delivering the objectives are ambitious challenges but ones which we are now prepared to take on.

We will keep you informed throughout and, in the meantime, the continued support from all those that are interested in our work is ever so important and we hope you will be as enthusiastic about the future as we are. From all of us at Give a Kidney we wish you and all those close to you a very joyous festive season and, of course, a healthy and happy coming year.

Bob Wiggins, Chair of Trustees

Reaching milestones...

The ‘ultimate endurance ride’ for cyclists of 500 miles in six days, marks a milestone for Give a Kidney too: the 1000th non-directed kidney donation

Do you love cycling? Can you help Give a Kidney raise awareness of living kidney donation by doing what you love?

In September 2023, a group of up to 30 cyclists are invited to ride from Edinburgh Royal Infirmary to the Churchill Hospital in Oxford, as part of the Transplant Tour. Cyclists will call at seven of the UK’s Transplant Centres in Edinburgh, Newcastle, Leeds, Sheffield, Manchester, and Birmingham before ending in Oxford six days later, taking in some beautiful scenic routes on the way. At the end of each day’s cycling, there will be a social gathering with a chance for the cyclists - and any non-directed donors who would like to join them - to meet the dedicated staff at the Transplant Centre. At the end of the journey, at The Churchill Hospital in Oxford, cyclists will be greeted with a small celebration event.

It’s not a race, it’s a test of endurance, so participants need to be pretty fit before they start.

The aim of this inaugural event is to raise awareness of living kidney donation to a stranger. Since it became legally possible to do this, around 1,000 people in the UK have stepped forward to help someone suffering with chronic kidney disease and kidney failure, so the *Transplant Tour* will coincide with the celebration of this notable milestone.

The event is being organised by Funraising Tours, a company set up in 1999 by non-directed kidney donor Dennis Carver with the aim of raising funds and awareness

THE TRANSPLANT TOUR 17-22 September 2023



of various charitable causes through cycling events. For 2023 the chosen charity is Give a Kidney.

Participants should be over 18 years and will need to raise £1,000 for Give a Kidney through sponsorship (paid direct to the charity) and cover the costs of the trip: £675 for accommodation, support, lunch etc. en

route – which could also be raised through additional sponsorship. All the details of this event are on the Funraising Tours website, along with information on how to apply to take part: www.funraisingtours.co.uk

Unfortunately, as I write in November 2022, we face the sad situation that transplant waiting lists in the UK continue to increase following the pandemic and there is an upward trend in the number of people waiting for a kidney.

Deceased donation rates are affected by falling consent rates. This is obviously concerning and is being looked at carefully so that we have a better understanding of why it is happening. One thing is clear: it is still really important in the opt-out system that everyone registers their donation decision on the Organ Donor Register and that they have shared that decision with their family.

In living donor transplantation, recovery post-pandemic remains strong overall, and has now returned to about 80% of pre-pandemic activity, with all UK centres contributing. Quarterly matching runs of the UK Living Kidney Sharing Scheme (UKLKSS) are fully reinstated. The latest run (October) generated 89 transplants and included 22 non-directed living donors.

Behind the scenes, we have been busy developing a significant living donation Digital Transformation Programme, which

initially aims to address safety and sustainability in the UKLKSS by automating the current manual, paper-based processes associated with the scheme. Subject to funding, we hope that further stages will enable us to scale up the UKLKSS to increase transplant opportunities, benefit more patients and to improve data collection throughout the living donation pathway and for life-long donor follow-up.

In other areas of transplantation, after many years of groundwork to develop a strategy for Living Donor Liver Transplantation (LDLT), a Project Board was established in April 2022 to take forward this initiative in line with the actions detailed in the 'Organ Donation and Transplantation 2030: Meeting the Need' strategy. The purpose of the project is to deliver a UK-wide programme that improves access to LDLT as one of a range of transplant options for adults and children with end-stage liver disease (ESLD). Four workstreams are in place to produce recommendations, for endorsement by the wider community; about models of service delivery; management of donors and recipients; and

educational requirements for professionals, potential living donors and recipients about LDLT. Of course, Give a Kidney was heavily involved in the development of educational materials for living kidney donors and we hope to use everything we have learned through that process to inform the way in which we approach educational material about living liver donation. Jan Shorrocks has kindly agreed to contribute to the Education Workstream on behalf of Give a Kidney, and the new materials will include information on non-directed living liver donation.

On a really positive note, we are looking ahead to the 1,000th non-directed living kidney donation during next year and working with Give a Kidney to ensure that we make the most of this opportunity to raise awareness and engage the public in thinking about non-directed donation. Thank you to everyone who has played their part in this great achievement which would have been impossible to imagine when I started with NHSBT in 2010.

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



Living Donor Co-ordinator Induction

It was a great pleasure for our Executive Officer, Jan Shorrocks, to once again be invited to speak on the annual induction session for new-in-post UK living donor coordinators, which was held in Bristol recently. This will be the second consecutive year that Give a Kidney has been part of the agenda, which we hope will become an annual invitation. The session provides an opportunity to highlight to new coordinators some of the aspects of the process that we think are particularly important or challenging, based on what we hear from the lived experience of donors. It also introduces us as a charity who can offer additional support and information to the donors these coordinators will work with and allows us to build new contacts and relationships with coordinators. Thanks to Lisa Burnapp and Living Donor Transplant Co-ordinator Jen Lumsdaine for the invitation.

We're very excited to announce that our first webinar of 2023, via Zoom, will be on the fascinating subject of ethical issues in transplantation. Sign up here: <https://bit.ly/gak-ethics-webinar>

Ethical issues in transplantation

Winter Webinar series
2022/23



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



Dr Antonia Cronin, Clinical
Research Consultant
Nephrologist, NIHR
Biomedical Research
Centre, Guy's & St Thomas'
NHS Foundation Trust



Dr Miran Epstein,
Reader in Medical
Ethics, Queen Mary,
University of London



Dr Greg Moorlock, Associate
Professor, Bioethics and
Academic Lead for the
Values, Law and Ethics
Theme of the MBChB,
Warwick Medical School

Tuesday 24 January 2023
7.15pm, via Zoom



Organ Trafficking and Tourism - The Sad Reality

With more people in need of kidney transplants than the number of donor kidneys available, a recent news story highlights the unsavoury consequences of having this gap between supply versus demand. The news piece cited here from The Guardian,¹ but shared across



many media platforms, reported on the case of a Nigerian politician and his wife being arrested on charges of trafficking a homeless 15-year old boy to the UK to harvest his organs.

Organ trafficking and tourism are a sad reality of the chronic shortage of organs for transplantation. Although international transplant groups all subscribe to the Declaration of Istanbul,² a statement that promotes and aims to uphold the adoption of ethical transplantation around the world, unethical organ donation and transplant does occur. Being clandestine in nature, getting hard figures is difficult to obtain but for criminal organisations it is a lucrative trade. According to the Global Finance Integrity group,³ it is estimated that the illegal trade of human organs generates about \$1.5 billion US dollars each year from roughly 12,000 illegal organ transplants but actual figures could be much higher. Many vulnerable individuals are particularly susceptible in different areas of the world, with North and West Africa a particular concern as highlighted in this particular news story and flagged by Interpol as a matter of concern.⁴

Perhaps the most shocking example of forced organ harvesting occurs in China. There is now a significant amount of evidence, both from legal tribunals (<https://chinatribunal.com>; <https://uyghurtribunal.com>)

and investigations by United Nations human rights experts,⁵ that organs for transplantation in China are obtained from the killing of prisoners. These prisoners may be incarcerated for actual crimes or simply for their beliefs (prisoners of conscience). While China claims that since

1st January 2015 they no longer take organs from executed prisoners, the evidence would suggest this isn't true and that widespread trans-plant abuse occurs across many hospitals in China. As Secretary of the international non-Government organisation Doctors Against Forced Organ Harvesting (DAFOH; <https://dafoh.org>), our group raises awareness of these issues for the global medical and transplantation community and lobbies international groups, organisations, and industry partners to try and bring this unethical practice to an end. The group was nominated for the Nobel Peace Prize in 2016 and 2017 for its work in this area, and in 2019 it received the Mother Teresa Memorial Award for Social Justice in recognition of its work.

Sadly, as long as a global shortage in organs required to meet the need for transplantation exists, there will always be individuals and/or organisations willing to exploit the situation for financial gain. The best way to tackle this is to ensure every country becomes self-sufficient in the supply-versus-demand for organs. That is why the work of charities like Give a Kidney, raising awareness of non-directed (altruistic) living kidney donation to meet the urgent need for transplants, is so valuable. Kidneys are the most common organs transplanted and have the largest

waiting list for all countries. The special gift made by non-directed living kidney donors is playing a valuable part to directly improve the lives of kidney failure patients here in the UK. Indirectly, they are also contributing to saving the lives of vulnerable people across the world who are exploited for their organs by helping to bridge the gap between supply versus demand.

Dr. Adnan Sharif

Consultant Nephrologist (Queen Elizabeth Hospital Birmingham)

Honorary Reader (Institute of Immunology and Immunotherapy, University of Birmingham)

Trustee, Give a Kidney

In the Media

Following some good media activity around Organ Donation Week, we are currently working on a number of pieces with a national publication which should be out in the next couple of months. In one piece, the journalist speaks to a number of non-directed donors about their decision to donate; another focuses on a non-directed donor and her recipient; and a third focuses on healthcare professionals who have chosen to donate one of their kidneys to someone they don't know – a very reassuring message we feel.

We'll include the links in the next newsletter, or follow our social media channels in the meantime to keep up to date.

In other news, as Lisa Burnapp mentions elsewhere, we're now looking forward to the opportunities presented by the upcoming 1,000th non-directed donation, which we anticipate being in the next few months. Many of you will have been involved in previous celebrations around the 250th and 500th non-directed donation and, as ever, we hope to maximise the opportunity this presents to garner press and public interest in non-directed donation. Watch this space for more information on how you can get involved, but we would certainly encourage you to think about ways you might like to help us celebrate this very significant milestone in your own communities.

References

- 1 *The Guardian*. Nigerian politician accused of trying to bring boy, 15, to UK to harvest organs. <https://www.theguardian.com/uk-news/2022/jun/23/man-woman-charged-trying-bring-child-uk-harvest-organs>
- 2 *The Declaration of Istanbul on Organ Trafficking and Transplant Tourism (2018 Edition)*. Transplantation 2019;103(2):218-219. DOI: 10.1097/TP.0000000000002540.
- 3 *Global Financial Integrity 2017*. Available online: <http://www.gfintegrity.org/wp-content/uploads/2017/03/Transnational-Crime-final.pdf>
- 4 INTERPOL. North and West Africa: INTERPOL report highlights human trafficking for organ removal. <https://www.interpol.int/en/News-and-Events/News/2021/North-and-West-Africa-INTERPOL-report-highlights-human-trafficking-for-organ-removal>
- 5 UN Special Rapporteur report letter to China on 10 June 2021: REFERENCE AL CHN 5/2021: <https://spcommreports.ohchr.org/TMRResultsBase/DownloadPublicCommunicationFile?gld=26382>

Funds like this help our small charity continue with activities such as our free webinars, like the ethics one we're holding next month. See page 3 for more details.



As a GP (now retired) Giles was very aware of the lives that his patients on kidney dialysis (and their families) had to endure, sometimes for years. He gave his right kidney altruistically 12 years ago and has never regretted it. Both Giles and his recipient are well. His family were not altogether supportive of his donation and they felt the same about him running the London Marathon but he promised this would be his last as he has just turned 75! Giles successfully completed the London Marathon on the 2nd October 2022 and in so doing raised over £900 for Give a Kidney. Well done Giles! His Just Giving page is still open should you wish to make a belated donation - <https://www.justgiving.com/fundraising/giles-smith4>

Debbie Stewart's Challenge for Give a Kidney

Debbie Stewart had been wanting to do some fundraising this year for Give a Kidney to mark the anniversary of her donation to a stranger. She didn't take the easy option: she cycled 100km a day to raise awareness and much-needed funds for the charity.

Debbie had first enquired about donating in 2016 after reading an article about it but it wasn't until 2019 that she felt fully ready, receiving the all clear from tests just as COVID19 hit in early 2020!



A good match was eventually found and she donated into the kidney sharing scheme.

"Whilst I don't know who has the kidney I donated, I just hope that they are doing well, and that it's changed their life as much as I hope it has" she said.

"I know from the feedback that I've received that most people would do it for family, but they would not do it for a stranger. My argument to that however is that there are so many people out there that perhaps do not have family, or no family who are a match for them, and so have to rely on the gift of life from strangers instead.

"It's the most powerful thing I have ever done and likely will ever do" she concludes. Despite Debbie acknowledging that her fitness had taken a hit this year, she managed to cycle 1,000km over the course of ten days, and raise more than £600 for Give a Kidney. An amazing achievement, we're sure you'll agree. You can still donate here <https://www.justgiving.com/fundraising/Debbie-Stewart22> should you wish to.



Q Can I claim expenses as a non-directed living donor?

Yes, you can claim certain expenses that are incurred as a result of being assessed or becoming a living donor, such as loss of earnings and travel costs. You should discuss this with your living donor coordinator early on in your assessment process, as you will need to provide appropriate evidence. Your coordinator can talk you through what support is available and how to claim it.

Q Do non-directed kidney donors save the NHS money?

The short answer is yes. It is estimated that the cost benefit of kidney transplantation compared to a patient being on dialysis over a period of ten years is £241,000. More information about the financial implications of transplants and the money saved can be found here - <https://bit.ly/NHSBTtransplantcostsavings>

Nicholas Evans



We were saddened to hear of the passing of Nicholas Evans in August of this year.

*Nicholas Evans
Credit: Nicholas Evans
wordpress*

Nicholas played a pivotal role in helping Give a Kidney become an established charity in its early days, for which we are very grateful.

Our thoughts are with his family and friends at this difficult time.

Got any ideas for future articles or news you'd like to share? Please send copy to info@giveakidney.org

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Give a Kidney is a registered charity in England and Wales (1195852)