

#shareyourspare

Update from the Chair

So much to say ... so little space! Four pages won't do justice to fully convey all we have done, are doing and planning to do. Nevertheless these pages will give you a flavour, if not the full stories and their impact, in particular:

- How personal stories created a chain of new donors – see Lisa's and Juliette's stories.
- How collaborating with other organisations can create enormous synergy and opportunity as in the newly-launched Robert Dangoor Living Kidney Donor Programme.
- The fantastic efforts people go to in order to support our much-needed fundraising efforts – special thanks to Dennis Carver (see page 4) and all our fundraisers.

2023 was an incredible year for achieving a step change towards our vision of "no waiting for a transplant for want of a kidney" leading up our celebratory supporters' event in November. We also celebrated the 1000th non-directed living kidney donor since the first in 2007. With the support of people like Lisa, Juliette, Dennis and David Dangoor we will surely

reach the 2000th donor in a fraction of that time.

I cannot overstate the incredible progress, on so many fronts, for Give a Kidney over the past 12 months. The Trustees' strategy day in July 2022 set our ambitions for the next one, five and 10 years. These fantastic plans which were only limited by lack of funds and people made it equally inspiring and frustrating. A mere six months later and we were in discussions for what would become a major strategic collaboration to implement much of that five-year strategy. One year on, and we have launched the Robert Dangoor Living Kidney Donor Programme made financially possible by David Dangoor and made deliverable by combining resources with our partner Kidney Research UK (KRUK). KRUK brings substantial organisational expertise in project management, human resources, IT systems, marketing and fundraising, whilst Give a Kidney provides the equally important wealth of lived experience




Bob Wiggins, Chair

and knowledge of living kidney donation as well as the trust and support of the entire transplant community.

This programme is both exhilarating in what it can achieve and daunting in scale and pace. As the programme tackles existing challenges to living donation, it will also present new challenges for us to meet.

Finally, as we begin 2024, it is appropriate to recognise and thank all those who have helped us on our way: David Dangoor and Dennis making this giant step forward possible, the supporters at our autumn celebration event including the Black Living Donor Choir and all those who have been able to tell their own living donation story, And none of this could have happened without the tireless efforts of our team of Annabel, Jan, Lou and Viv, the Robert Dangoor team of Emma, Eoin and Jenny (see more on page 2), our friends at KRUK and as always, Lisa Burnapp who remains central to our successful and effective collaboration with NHSBT.

Bob Wiggins, Chair of Trustees



The Robert Dangoor Living Kidney Donor Programme launches with the 'Make Your Mark' campaign (read more on page 2). To find out more, visit www.donateakidney.co.uk or follow on X, Facebook or Instagram @DonateaKidneyUK

The UK's 1000th Non-directed Kidney Donor



2023 saw the UK's 1000th non-directed donor, a milestone worth celebrating.

Together with NHSBT we have been in contact with the 1000th donor and are jointly dealing with media to place the story this month (February).

Keep an eye on our website or follow us on Facebook, 'X' or Instagram (and subscribe to our YouTube channel) where you can discover all our latest news.

A belated 'Happy New Year' and I hope that 2024 is a good year for each and every one of you who give so generously of yourselves and of your time to support patients waiting for a transplant through living donation.

Sadly, waiting lists have continued to rise in the aftermath of the COVID-19 pandemic: currently, there are 5,700 people waiting for a kidney in the UK. On a more positive note, deceased donation activity is above where we thought it would be for this financial year (April to March) and living donation is on track to deliver more than 900 transplants, mostly kidney recipients, by the end of March 2024.

No update would be complete without reference to the contribution that non-directed donors make to our living donation programme. Latest reports show that 63 non-directed altruistic donors donated in 2023, which was fewer than 2022 (71) but the same as 2021, suggesting that there may have been some delayed donations from the pandemic years that went ahead in 2022. Last year, 42 non-directed donations triggered a 'chain' in the UK Living Kidney Sharing Scheme (UKLKSS), generating 66 additional transplants. So, despite fewer donors in 2023, we saw an

increase in transplants (108 vs 103 in 2022) because more 'three transplant chains' than 'two transplant chains' were unlocked in the UKLKSS. It really is a case of every donor brings something different to the party!

A big focus in the past year has been delivering LivingPath, a digital platform to replace all the manual processes that support the UKLKSS and to create the opportunity for future transformation. LivingPath supports the management of donor and recipient data and information within the UKLKSS before and after it is submitted into the matching algorithm. LivingPath will improve informed decision-making and communications between clinical teams, transplant laboratories and with NHSBT to make the most of every transplant opportunity. Enormous credit is due to everyone involved in this project - too many to mention here - and to living donor teams and laboratory staff who have borne with us through the transition period.

In 2024, we look forward to marking some milestones in non-directed donation and to creating many more in collaboration with Give a Kidney and with the launch of the Robert Dangoor Living Kidney Donor

Programme. We are currently reviewing and updating our <https://www.organdonation.nhs.uk/become-a-living-donor/> website, and focusing on key diary dates and activities to raise the profile of living donation. A new 'Proctor Programme', to enable the expansion of living donor liver transplantation, is also about to be launched to offer patients better access to this choice across the UK.

In other news, I am delighted that Jen Lumsdaine, already known to many of you because of her work in Scotland supporting living donation, will be joining me as Lead Nurse - Living Donation at NHSBT two days a week later in the Spring. Jen has a wealth of experience and will be a huge asset to the team. She will retain her role in Scotland alongside her new appointment.

Finally, a huge thank you to all of you for your continued enthusiasm and support; the act of non-directed donation is the 'gift that keeps giving' and we need you all more than ever. We can't thank you enough.

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



Update on the Robert Dangoor Living Kidney Donor Programme

As our supporters will be aware, Give a Kidney has joined forces with Kidney Research UK to deliver the Robert Dangoor Living Kidney Donor Programme, made possible by businessman and philanthropist David Dangoor CBE. David is particularly invested in raising awareness of living kidney donation having previously donated a kidney to his brother Robert.

The programme has been created to raise awareness and encourage more people to consider donating a kidney during their lifetime. The programme will be working closely with support from NHS Blood and Transplant.

Together, the two charities will endeavour to help more people understand what it means to be a living donor, as well as supporting and guiding them throughout their donation journey.

There has been a huge amount of work

going on behind the scenes for the best part of a year by the two charities, together with the Programme Team of Emma Hotchkiss (Programme Lead) and Eoin Buckley (Marketing and Communications Manager), who joined the programme in Autumn 2023.

We are delighted to also welcome Jenny Waters, the Living Donation Relationship Manager. She joined the Programme Team in January, and her role will be as first point of contact for the programme for potential living donors, as well as developing and managing the new buddy system for potential donors and their family members.

The programme launched at the end of January, supported by a significant marketing and communications campaign, with the strapline *Make Your Mark*. It is underpinned by a fantastic new website

to guide and support people through the journey of living donation, with a sophisticated new Customer Relationship Management System behind it.

A number of Give a Kidney supporters have already been involved in various ways in the campaign planning and we thank you for all your support. There will be more opportunities coming up including the recruitment for 'buddies' in the Spring, so do watch this space to find out more about getting involved.

This is a hugely exciting programme and will very much take forward the work undertaken by Give a Kidney over the last decade to a whole new level, with significant funding behind it.

Visit www.donateakidney.co.uk or follow on social media (details on page one) and please spread the word.



*Emma Hotchkiss:
Programme Lead*



*Eoin Buckley: Marketing &
Communications Manager*



*Jenny Waters: Living
Kidney Donation
Relationship Manager*

Events

We always welcome feedback on future supporters' events and locations, so please email us at info@giveakidney.org with your comments.



Supporters' Event

In November, we were delighted to welcome old friends and more recent donors to our Supporters' Event in the beautiful setting of the Crypt in the Green, St James's Church in Clerkenwell, London.

This was the first time we had gathered in person for more than four years, since before the Covid pandemic. Guests appreciated time for informal discussion and to hear the latest exciting updates that are happening. A big thank you to Emma and Eoin for providing an update at that stage on the Robert Dangoor Living Kidney Donor Programme, to members of the Living Donor Choir who gave a great insight into their work, and to Dennis who offered a snapshot into the huge success of the Transplant Tour 2023.

If you would like to hear about our forthcoming events, please sign up to receive all our news: <http://eepurl.com/hqyjKj>



The European Society for Organ Transplantation • ESOT Congress

Last September, Give a Kidney was delighted to accept an invitation to present at the European Society for Organ Transplantation's (ESOT) biennial Congress, which took place in Athens, Greece.

The ESOT Congress is the most influential and major event of its kind, with hundreds of participants attending from all over the globe to discuss, debate and explore the latest trends in the world of transplantation. Serving as a leading platform to exhibit best practice and research, the meeting delivers world-class science and education whilst offering vast networking opportunities at an international level. Many other countries in the world do not have living donor programmes, so it was a wonderful opportunity to share our learning and advocate for living kidney donation, as well as an excellent networking opportunity.

The theme of the Congress was *Disruptive Innovation, Trusted Care*, and Give a Kidney was invited to present in a session entitled *Patient Pioneers* to reflect on the early days of non-directed living kidney donation in the UK. We were delighted that Kay Mason, the UK's first non-directed donor, agreed to join



Athens September 2023

us to share her memories of advocating for non-directed living donation in the UK, and her personal story of becoming the first donor of this kind in 2007. Our Executive Officer, Jan Shorrocks, then spoke on Give a Kidney's work over the last 12 years, including the importance of working collaboratively with transplant professionals. The presentation was well received, and led to many other conversations and questions outside of the presentation hall.

The remainder of the conference was a packed programme of sessions and presentations on all areas of organ donation and transplantation. A particular highlight was hearing from the person to have the world's first double arm transplant, Felix Grétarsson, who lost both arms in 1998 in an accident at work as an electrician. There was not a dry eye in the house when he shared his experience of hugging his daughter again after more than 20 years. A hugely humbling reminder of the life-changing impact of transplantation.

Many thanks to the organising committee for the invitation, and the opportunity to share our insight and experience and learn from transplant professionals and other patient group representatives from around the world.



Transplant Tour

Following a hugely successful 2023 Transplant Tour which raised more than £34,000 for our charity, we are delighted to announce that the organiser, Dennis Carver of Funraising Tours, has launched the Transplant Tour 2024!

The Tour will again visit seven transplant centres – Cardiff, Bristol, Oxford, Coventry, Leicester, Cambridge and London – but the route has been reduced to 400 miles and much of the climbing has been eliminated. So, if you're an amateur cyclist or want to take on a fitness training challenge in the New Year, or perhaps you know a friend or family member who could take on this challenge, please get in touch with Dennis, and you can find out a little more about what the Tour involves (there is great video coverage from this year's Tour!) - dennis.carver@btinternet.com

We are so grateful to Dennis – who only recently put his feet up after cycling 500 miles continuously for five days on the last Tour – for organising another fundraising and awareness initiative for Give a Kidney.



Top: Paul van den Bosch (left) with Dennis Carver
Main photo: the Transplant Tour cyclists

15 years after donating his kidney to a stranger, Transplant Tour participant and Give a Kidney Trustee, Paul van den Bosch told BBC Radio Sussex that he remains “fit and well, still working and still cycling regularly”. Listen here: <https://www.bbc.co.uk/sounds/play/p0h0cp49>



Talks that inspire...

Give a Kidney fundraiser Lisa recently shared her story of non-directed organ donation on BBC Radio 4 and how she was first prompted to come to this decision after hearing John Fletcher's story more than two years ago on Clare Balding's *Ramblings* radio programme.

This is why we're always so grateful to people sharing their stories with us - we may not always know when it has resonated with someone, and it can take some time from when they hear the story to one day donating to a stranger, but personal stories really impact.

If you would like to share **your** story with the public, please email us: info@giveakidney.org

Meet Juliette...

We were delighted to meet Juliette and her parents at our Supporters' Event. Juliette is a new supporter, having donated her kidney to a stranger in 2023.

Juliette works as a Research Manager in a large London university. Having been a blood donor since she was 17 and participated in many research trials at work, she felt it natural to enquire about altruistic donation. She had considered waiting a few years, but after some consideration, she decided to go ahead with the operation. As she says, “I had no dependents to look after during the recovery process and was able to work from home, instead of rushing back to the office.”

Juliette says the whole process has been extremely positive, and adds: **“The donor team were incredible, always keeping me well informed and easy to contact when I had queries”**. Read her full story at <https://www.giveakidney.org/2023/personal-stories/donating/juliette/>



In the Media

The Transplant Tour received great coverage, below are just some of the articles and radio interviews that captured the event:

Thackray Museum of Medicine:

bit.ly/3SnKSxP

BBC Sounds:

<https://bbc.in/48yIKJj>

I Love Manchester:

bit.ly/4b8ARMc

Wokingham Today

bit.ly/3u1TwJ3



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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)