

#shareyourspace

Introduction from our Chair

In the last newsletter I summarised the progress made over the past ten years, laying foundations, building credibility, establishing partnerships through collaboration – and, of course, supporting donors. I was remiss in not paying tribute to all those who made this possible from our founders, trustees, staff, partners and supporters, without whom this would not have been possible. Thank you!

I also set out our continuing drive towards our vision of “no waiting for a transplant for want of a kidney” and how we needed to set our ambitions ever higher. I acknowledged how this would require us to think big in terms of not only what we can achieve, but also how to secure substantially more funds with which to do so.

At the time of writing that introduction, I was unaware that, through the generosity of businessman and philanthropist Dr David Dangoor and The Exilarch's Foundation, we would be in a position to realise the significant impact we were looking to achieve. Dr Dangoor has personal experience of living kidney donation, having previously donated a kidney to his brother Robert.

We are delighted to be joining forces with Kidney Research UK (KRUK) to



Bob Wiggins, Chair

deliver a new national programme to support those considering donating a kidney by helping them fully understand what it means to be a donor, to supporting them throughout their whole journey.

Partnering with KRUK will bring a wealth of expertise, knowledge and skill to the new programme; our goal is to reach those people who, like many of us when considering donating a kidney would say ‘I could do that’. More than simply connecting with those people, in collaboration with NHS transplant centres, we will be looking to support prospective donors with tailored support through their individual pathway towards (and beyond) donation.

Each partner will bring unique skills to this innovative programme. KRUK have the capacity and capability to bring in the talent required, whether it be project management, marketing, technology, human resources or finance. Give a Kidney will contribute with its knowledge of living kidney donation, donors, recipients

or the NHS transplant community with its processes and procedures. Together we will be looking to complement and support NHS transplant centres and the work of NHS Blood and Transplant as we drive forward this ambitious programme to increase living kidney donation throughout the UK.

Whilst Dr Dangoor's willingness to contribute a large sum of money over the five years will cover the vast majority of the expected cost, it understandably comes with a commitment from Give a Kidney and KRUK to be a co-contributor. That commitment maintains the pressure on us to increase our own fundraising – in this case by 50%. Given the shortfall in income over the past few years we will need to find another £15,000 per year, but doing so unlocks this very significant level of funding. We have challenged ourselves to develop new funding sources, but will continue to rely on the generous ongoing help from all of our supporters.

Look out for updates throughout the coming months as we launch this new and exciting chapter for Give a Kidney that we have all been working hard to achieve.

*Bob Wiggins,
Chair of Trustees*

Volunteer needed!

Are you a kidney donor or recipient who's also an accountant, bookkeeper or other finance professional? If so, Give a Kidney needs you! Our small charity is looking for a Trustee Treasurer at what is a very exciting time for the charity as we embark on our campaign with the Robert Dangoor Living Donor Programme. The role will involve being actively involved with the day-to-day financial operations and management of the charity as well as the overall strategy.

The nature of the role means it does need someone who can commit to giving at least a day a month to the charity, although these hours can be done very flexibly. If this sounds like something that might be of interest to you, please contact the current finance officer in the first instance on giveakidneyfinance@gmail.com, who can provide more information and set up a time for you to have a chat with our Chair and current Treasurer. This is a voluntary role but all expenses will be covered.



I am very happy to report good news in this summer newsletter. Latest statistics show that the numbers of living donor transplants went up to 960 last year, which is 90% of pre-pandemic levels. This includes 83 non-directed altruistic donors, representing a 15% increase on the previous year. Activity through the UK Living Kidney Sharing Scheme (UKLKSS) also remains strong. This is fantastic news for every patient on the transplant list, even if they do not have a living donor of their own. On behalf of every patient waiting for a kidney, thank you to all of you for your generous gift of donation.

One of the priorities for NHSBT this year is delivering the first phase of LivingPath - a digital transformation programme to streamline everything we do in living donation from referral to donation. This first phase will remove the manual, paper-based processes in the UKLKSS, including the registration and management of donors and recipients, sharing information between transplant centres, quarterly matching run reports and a scheduling option for transplant centres to manage transplant dates for identified matches. The first 'release' of the programme, ahead of the April matching run, allowed living donor teams and laboratories to register donors and recipients in the UKLKSS directly into

the system for the first time and the next release is eagerly awaited later in the year. Huge thanks to everyone who has made this possible and to all our clinical colleagues - particularly living donor coordinators and histocompatibility and immunogenetics laboratory staff - who continue to support us through the design, development and deployment of this project.

In other news, we have made good progress with the living donor liver transplantation project. In February, the clinical community and patient representatives endorsed recommendations to develop the living donor liver transplantation programme for adult recipients across the UK. A proposal to support the roll-out is currently with commissioners awaiting funding approval. In the meantime, the project, led by NHSBT, will continue through the course of this year to focus on delivering educational resources for patients, potential donors and healthcare professionals, so that everything is in place to move ahead once we get the green light.

In the aftermath of the pandemic with waiting lists going up, the contribution of living donation, the hope that it offers to patients waiting for a transplant and the difference it makes to people's lives has become even more evident. I look forward

to continuing to work with you all on this critical agenda - to raise awareness and support people to consider living donation.

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



How can you support us?

While the funding from The Exilarch's Foundation is an incredible development for our small charity, there is an even greater need for regular donations, both for our contribution to the programme and to cover our core costs, such as accountancy fees, submissions to the charity commission, the cost of hosting our website and producing these newsletters.

"If everyone on our mailing list gave just £2 a month, all of our core costs would be covered."

If you are able to contribute to our work at this exciting time, please use this link <https://bit.ly/JGGAK> and pledge via Just Giving. Alternatively contact us on info@giveakidney.org and we can pass our bank details on for you to set up a standing order. If everyone on our mailing list gave just £2 a month, all of our core costs would be covered, and we could start to do more in terms of raising awareness, campaigning for change and providing more support to more donors - past, present and future.

We must add, we are tremendously grateful to all of our supporters who make a regular donation to Give a Kidney whether it's monthly or annually, as well as those who make one-off donations or fundraise on behalf of the charity. We would not exist without you and all of your donations make such a difference.

If you already give regularly via standing order or direct debit directly to the charity you should have recently received a gift aid form. We would be very grateful if you could complete, sign and return this asap if you have not already done so. Thank you.

Meet Richard...

Richard is a GP living in Nottingham and he donated his kidney to a stranger in 2022.

He says: "I was lucky enough to match into an altruistic donor chain of three people. I've heard from the hospitals in which the recipients had their donations that they're doing very well and that's the only reason that I decided to do this in the first place. That obviously brings an immense feeling of satisfaction as those people, whoever they are, no longer need dialysis three times a week and they can hopefully go about their lives in the way that they would do, whatever that involves for them.

But beyond that I feel just like I used to. It certainly doesn't feel like a big thing to me.



"I'd say that donating a kidney to a stranger is a big deal but a temporary big deal. It's something that normal people just like me can do in a section of their lives and it can bring a huge amount of benefit to the people that receive the kidney and

all their friends, family and loved ones.

"So you don't need to be a superhero, you don't need to be a mega star of any sort - this is potentially available to a large number of people and I recommend that people think whether or not it's something that they can incorporate into their own lives."

Read Rich's full story here:
<https://bit.ly/43HRo5P>

Many thanks to those who joined us for our Winter Webinar Series. First up was 'What are the ethical issues in organ transplantation?' with guest speakers, Dr Adnan Sharif, Give a Kidney Trustee and Consultant Nephrologist at Queen Elizabeth Hospital in Birmingham; Dr Antonia Cronin, Clinical Research Consultant Nephrologist at the NIHR Biomedical Research Centre at Guy's and St Thomas' NHS Trust, Dr Miran Epstein, Reader in Medical Ethics at Queen Mary University of London; and Dr Greg Moorlock, Associate Professor in Bioethics at Warwick Medical School.

Our panel discussed some of the biggest ethical issues in transplantation today with discussion around subjects as wide ranging as social media, technological advances in transplantation, and transplant tourism.

The second webinar of the series was of a 'back to basics' nature which three of our trustees hosted – Adnan Sharif, Paul Gibbs and Caroline Basarab-Howarth. They answered a



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

variety of questions around non-directed living kidney donation including what the operation consists of, whether there is any policy for someone who has donated a kidney and then requires a transplant themselves and the nature of the post-

operative care.

Both webinars are on our YouTube channel, and please subscribe, if you haven't already, to receive notifications when any of our videos go live. Visit: www.youtube.com/@giveakidney

Give a Kidney represented at ESOT

Our Executive Officer, Jan Shorrock and Kay Mason, the UK's first non-directed living donor, will be speaking at The European Society for Organ Transplantation (ESOT) Congress in Athens this September. The ESOT Congress is the most influential and major event of its kind, with participants attending from all over the globe to discuss, debate and explore the latest trends in the world of transplantation.

Jan and Kay will speak in the seminar "Patient Pioneers – those who dare to go first". As non-directed donation is not routinely offered in many European countries, Jan will be shining the spotlight on the UK work in this field. Kay has agreed to speak about her work in lobbying the Department of Health and Parliament to clarify the legal position on non-directed donation and how it was to be the UK's first non-directed donor back in 2007.

Edinburgh meet-up to commence the Transplant Tour

Cyclists participating in the Transplant Tour (see more on page 4) will start their six-day ride from the Royal Infirmary of Edinburgh on 17 September. Give a Kidney Chair, Bob Wiggins, who is also participating in the tour, will host an informal drinks event the evening before in central Edinburgh.

We would love to see any of our Scottish supporters at this event; if you are able to come, please email us at: info@giveakidney.org so that we have an idea of numbers.

The cyclists will also call at transplant centres in Newcastle, Leeds, Sheffield, Manchester, Birmingham, and finishing in Oxford.

Did you know?

The first kidney transplant performed in the Royal Infirmary of Edinburgh was in 1961, and indeed this was the first successful kidney transplant in the United Kingdom.



Training for Transplant Tour hits full pace



We are extremely grateful to Dennis Carver who has organised the Transplant Tour to raise funds for our charity, after coming up with the idea following his donation at the Churchill Hospital in 2021. Dennis knew he couldn't donate again as a living donor and has instead drawn on his previous experience in organising long-distance cycle rides for charities.

Dennis has recruited 14 other riders (riders will either cycle the whole event or join for certain legs of the Tour) for the event - including Give a Kidney's Chair Bob Wiggins and Treasurer Paul van den Bosch. Others in the team include kidney recipients at Edinburgh, Newcastle and Manchester who will cycle some way with the group and take part in the baton relay. This idea came from Sarah Lundie, a living donor coordinator at The Royal Infirmary of Edinburgh and it's meant to symbolise the giving and receiving of a kidney.

There are up to six kidney donors among the group, three of whom will be cycling the whole 500 miles, proving that giving a kidney does not impact adversely at all on one's life.

What training looks like

As part of the lead up to the event, which averages 83 miles a day, Dennis and the others have started cranking up the miles. A regular cyclist, even during winter, Dennis and his friend, Andrew, usually ride



a 35-mile circuit two or even three times a week. Building on this, in June they took part in their local Rotary Club ride in Berkshire, called the Three Counties Cycle ride, taking them on a 54-mile ride around the local countryside from and back to Bracknell.

This distance will be the new norm, at least once a week until 75 or 80 miles is reached and others taking part will be invited to meet up.

Want to support the cyclists?

To raise awareness of living kidney donation, the team has set a target of £20,000 in donations for Give a Kidney. The team has its own JustGiving fundraising page so if you would like to donate a few pounds to spur them on in training, or just to send a 'good luck' message, please visit: <https://www.justgiving.com/team/transplant-tour>

Our huge appreciation goes to Matt Johns who ran not one, but TWO marathons back to back on the weekend and has so far raised more than £1,700 for Give a Kidney. This is Matt's way of saying thank you for the UK Living Kidney Sharing Scheme, which his father has benefited from. Thank YOU, Matt! If you would like to donate to Matt's mammoth runs, visit: Matt Johns is fundraising for Give a Kidney CIO - <https://bit.ly/44tczs8>



Matt Johns

Sarah completes a triathlon for Give a Kidney

A big thank you to Sarah Lovegrove who walked, cycled and kayaked to raise funds for our charity – and this is after donating a kidney to a stranger in 2022. Sarah completed the trio of activities along the River Wey and covered approximately 50 miles in two days.

Sarah was extremely grateful for the support she received from Give a Kidney, and in particular our Trustee, Kiran, throughout the process, so she wanted to find a way to give back to our charity. You can read Sarah's story on our website here: *I'm glad I was well enough to donate my kidney to a stranger* (www.giveakidney.org).

If you would like to support her in any way, Sarah's JustGiving page is still live at <https://www.justgiving.com/page/sarah-lovegrove-1684355315149>



Our thanks to Tracey Joliffe

A big thank you to Biomedical Scientist Tracey Joliffe for donating a sum of money she received for giving a talk at a microbiology training day and to Gary and Nicola of 'Just Job It' in Doncaster, who have made Give a Kidney their chosen charity. Visit their website at www.justjobit.co.uk



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

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