

news

Autumn 2020 edition no. 30

www.giveakidney.org

NHSBT's UK-wide perspective on COVID-19's impact, and the implications for transplantation

January 2020 had been a phenomenally successful month because of the Kidney Sharing Scheme transplants identified in the previous October run. Until COVID-19 struck in mid-March, living donation activity was expected to be up on the previous year and non-directed donors to exceed more than 100 for the first time in five years. Then everything stopped. In consultation with clinical teams, NHSBT allowed individual Transplant Centres to assess whether they could stay open or not,

with the safety of patients and living donors at the heart of their decisions. Although retrieval of organs continued and some transplant programmes - such as liver and heart - were sustained, most kidney transplant centres closed to deceased donation and all living donor kidney transplant programmes were paused almost immediately. Clinical teams were redeployed elsewhere to support the 'front-line' and manage other patient services. The few centres that stayed open continued to perform transplants under very controlled. safe conditions.

Living donor kidney transplantation resumed at the end of May with Leicester Hospital being the first and ten Centres were open by the time of the Give a Kidney AGM on 18 July.

It has been a steep learning curve throughout the crisis but NHSBT and the whole donation and transplantation community has had an opportunity to reflect upon what went well and what, with the benefit of knowledge and experience, could be done differently in future. In terms of living donor kidney transplantation, every transplant centre was asked to come up with a plan as to how they could address the backlog of kidney transplants, including those identified in previous matching runs, together with a

contingency plan for the next surge or crisis.

NHSBT was also concerned about the impact on potential living donors and their approach to donation in the COVID era. With the help of Jan Shorrock and clinical colleagues a market research survey to assess how past, present and future living donors felt, was disseminated through Give a Kidney and other charitable networks plus social media. 240 responses were received across a wide range of donors of



different ages and with a good geographical spread. Most respondents were pragmatic about their personal vulnerability, being more concerned about the health risk to recipients. They were very keen for the transplant programme to restart but highlighted testing and personal protection equipment as key priorities.

Importantly, people were prepared to be flexible as to where they donated and where they were looked after - they clearly trusted the clinical teams across the country, regardless of where their own donor assessment had taken place. Currently this sort of practice is uncommon, but the survey showed that enabling transplants to happen was more important to donors than donating in their local centre. Recipients of

kidney transplants have also, anecdotally, said that they would be willing to move - QAH Portsmouth did this successfully with one of their patients who was transferred to Oxford, one of the few centres that remained open for kidney transplantation during the pandemic.

The BAME community was underrepresented in the survey (85% of respondents were white British). However, a local survey conducted by Dela Idowu (Gift of Living Donation) revealed fears amongst

> Black people of succumbing to the virus because of the impact of COVID-19 on Black and Asian people.

> At the time of writing, all transplant centres are open to living donor kidney transplantation and 'business as usual' is resuming. A kidney matching run is planned for the end of October 2020 - the first for nine months. It has taken longer for living donation to recover in comparison with deceased donation because of local and environmental considerations and legitimate concerns about donor and

recipient risk. We know more about the virus than we did and, importantly, as some parts of the country start to experience a second wave, we are confident about the safeguards that are in place in our hospitals to keep patients as safe as possible.

One very positive outcome of the crisis is the collaboration between Transplant Centres which began on a daily basis as the endemic unfolded and really facilitated decision-making processes. Regular interaction between centres, NHSBT and commissioners has facilitated recovery and allowed Units to work within local constraints, but sharing data and knowledge between them to provide the best possible care for transplant recipients and living donors.

Ask the Experts: Living Kidney Donation Saturday 14 November, 10am [Zoom]

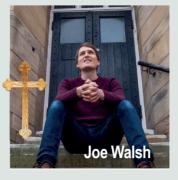
See details of this on-line event on Page 3.





Faith in Operation

Non-directed kidney donor Joe Walsh has written for the Church Times, Church of England newspaper and Christian Medical Fellowship during organ transplant week and has recently set up a website, Faith in Operation, to



encourage Christians to consider giving a kidney to a stranger.

Faith in Operation (FIO) would like the church to be instrumental in helping to save lives in this way, believing that the gift of life, our bodies, can be shared with those in need where possible.

FIO have produced a promotional video aimed at a Christian audience, to connect with them and gather stories of kidney donations to strangers. They encourage their readers to share the video on social media, or with their church, and to sign up to their newsletter.

Do you have any stories of Christian altruistic kidney donors? If you would like to get in touch, you can contact Faith in Operation via their website at **www.faithinoperation.co.uk**

Unspecified live kidney donation by urological patients

From the World Journal of Transplantation, 18 August 2020 Ceuppens S, Kimenai HJAN, Klop KWJ, Zuidema WC, Betjes MGH, Weimar W, IJzermans JNM, Dor FJMF, Minnee RC



Frank JMF Dor, MD PhD FEBS(Hon) FRCS

Since the first successful kidney transplantation there have been many efforts to increase the available pool of donors. Researchers hypothesised that patients, diagnosed with a benign kidney disorder that does not impair renal function, but still requires nephrectomy as treatment, may be suitable as live kidney donors.

Currently, patients with benign kidney disorder who undergo nephrectomy have three options: Auto-transplantation (AutoTx), discarding the kidney or living kidney donation.

AutoTx of these kidneys adds an additional surgical procedure with higher intraoperative complication rates and morbidity and without a clear benefit (unless indicated because of poor/marginal kidney function overall). However, if these kidneys can be successfully used in live kidney donation, the donor pool can be enlarged.

A search of clinical data from 1994-2019 for unspecified donors and their transplant recipients found that nine of the 160 donors had pre-existing kidney disorders necessitating nephrectomy and had decided to donate their kidney anonymously after discussing the possibility of kidney donation. The team studied the clinical course of these nine donating patients and their transplant recipients.

Seven of these nine donating patients indicated unbearable

Parallels drawn between living donation and the race for a vaccine for COVID-19

Recently a number of media articles have drawn parallels between the ethics of living donation and the 1 Day Sooner Campaign. This campaign advocates human challenge trials with carefully selected participants who, after being given a vaccine to be tested, would be deliberately exposed to a COVID-19 infection in order to speed up the research process. Such trials have been used for influenza, malaria, typhoid, dengue fever and cholera.

The campaign has been spearheaded by non-directed US kidney donor Josh Morrison, who has also campaigned to raise awareness of non-directed kidney donation in the US. The campaign estimates that finding a vaccine one day sooner would potentially save 1,250 lives worldwide, growing to an estimated 112,500 lives if a vaccine was found three months sooner. It makes the argument that speeding up the trial process by deliberately exposing vaccinated volunteers to the virus for research purposes has a clear benefit, that potentially outweighs the risk to the volunteers, perhaps in a similar way to the risk/benefit equation of living donation.

Of course, there are many differences in terms of what is known about living donation and its risks, as compared with the still relatively new and developing information we have on COVID-19, but it is likely that similar ethical dilemmas faced those early pioneers of living donation. It is interesting to consider the premise in terms of 'the greater good' that often, we hear, motivates non-directed kidney donors.

A week ago, the UK government announced they were actively supporting the idea with a plan to have challenge trials in place early next year. Nobody is actually recruiting for a challenge trial yet as it needs to be properly designed and ethically approved first, but you can sign up to the 1 Day Sooner UK petition expressing your interest.

To find out more about the 1 Day Sooner campaign, visit: www.1DaySooner.org Should anyone want to have an email discussion about the ethical overlap with kidney donation feel free to contact Paul van den Bosch, a Give a Kidney Trustee, at pandtvdb@gmail.com

loin pain as the main complaint, one donating patient refused ureterocutaneostomy that was otherwise indicated and one had two aneurysms of the renal artery. Postoperatively, seven donating patients described absence of pain and one a significant reduction after the nephrectomy.

In the transplant recipients, one major complication occurred which led to death and in one transplant recipient, graft function failed to normalize at first but has been stable for nine years now. Currently, all transplant recipients are off dialysis.

The research concluded that kidneys retrieved after nephrectomy from unspecified donors with urological problems are excellent donor kidneys. Long-term follow-up shows that these kidneys provide a safe and feasible option for enlarging the kidney donor pool, especially when initiating chains in kidney paired exchange. Future research should confirm these findings with a larger cohort.

Ask the Experts: Living Kidney Donation | Saturday 14 November, 10am [Zoom]

After successfully trialling our recent AGM online, we're now pleased to announce our next free online event – Ask the Experts: Living Kidney Donation, which will also take place on Zoom.

This is an opportunity for anyone considering living kidney donation or those going through the process, whether donating to someone you know, or anonymously to the waiting list, to have your questions answered by our team of experts. If you might need a transplant and are considering living donation, the panel will also be able to answer any questions you may have (although, for obvious reasons, will not be able to give specific clinical advice for individual cases).

We know that the process of thinking about donation can be very daunting, and many people have lots of questions and concerns before and during the process. We hope this event will be an opportunity to ask them in an informal and friendly setting. You can choose to remain anonymous should you wish to, and there's no pressure to ask, if you just want to come along to hear the answers to other people's questions.

We will be joined by Paul Gibbs, consultant transplant surgeon, Queen Alexandra Hospital, Portsmouth, Dr Adnan Sharif, consultant transplant nephrologist at the Queen Elizabeth Hospital Birmingham and Lisa Burnapp, clinical lead for living donation, NHS Blood and Transplant. There will also be someone who has donated a kidney recently, who will be able to share their personal experience of donation. We are very grateful to all of them for their valuable time and expertise.

To find out more, or to register, please visit our website at www.giveakidney.org/events

Belfast transplant team relocates operations during lockdown

What does a team of kidney transplant professionals do when their operating theatres are closed due to Coronavirus? That was the challenge facing the Consultants and nursing staff at Belfast City Hospital's kidney transplant centre when their unit was requisitioned to support the building up of 'Nightingale' facilities. Their response was to move the entire operational part of their service to Belfast's Royal Victoria Hospital two miles away.

Northern Ireland had been fortunate: the Irish sea had protected them from the initial

surge in England: COVID-19 was very low at that time and they were lucky to be able to relocate to a COVID-free hospital from the outset.

However, there were two immediate obstacles that needed to be overcome. Firstly, the in-patient beds and nursing staff were in the City Hospital transplant centre, with no facilities for looking after transplant patients in the Royal Victoria site. The Burns Unit there was willing to nurse the post-transplant patients, but staff had to take on a range of specialised duties for which very few had any previous experience. This had to be done carefully and progressively so as to maintain high standards of patient safety at all times. Secondly, the specialised equipment used in the transplant theatres had to be safely relocated to the Royal



The kidney transplant team's Dr Aisling Courtney (left) with surgeons Tim Brown and Hannah McGowan (©BBC News)

Victoria and made ready for use – not an inconsiderable task in itself – and the staff there given a rapid induction into transplant surgery which had never before happened in that hospital. Consultants made sure they maintained a continuous presence in the theatres and wards as far as possible, to provide education sessions and reassurance.

The reward for all this effort was two successful transplants. Building on this success, shortly afterwards the team carried out two more. Then, another four. And from that point on the whole operation went into high gear – over the seven and a half weeks that the team worked from their new 'premises' they carried out almost 30 transplants - an astonishing one third of the total number for the whole UK.

Dr Aisling Courtney commented that the new working arrangements resulted in

considerable extra demands on staff - demands that were met by everyone involved stepping up to work longer and harder. For example, the whole transplant pharmacv team began working weekends on-line methods communication were adopted patients support relatives and keep them informed. One experienced transplant theatre nurse came out of retirement to help set up the temporary operation at the Royal Victoria, making a key

contribution to the success of the enterprise.

The out-patient care after discharge was also a challenge, particularly because of social distancing restrictions and the sheer volume of newly transplanted recipients needing frequent review. Again staff were innovative, readily modifying their usual practices and running clinics at weekends.

To have delivered such an outcome in the midst of a global pandemic, when most of the country was going into lockdown, is astonishing. More than that, their determination to simply not allow obstacles to stand in their way, combining hard work and innovative approaches to progressively overcome each one, is the hallmark of an inspirational team.

From an article by Chris Jones, Chair, Give a Kidney Scotland

Transplant surgeon Paul Gibbs reflects on a challenging few months...

At Give a Kidney's on-line AGM in July, vascular and renal transplant surgeon Paul Gibbs, who is also a Trustee of the Charity, illustrated the difficulties that had been

experienced at his hospital, Queen Alexandra Hospital in Portsmouth. It had proved a 'very testing time', with the transplantation programme having to be temporarily suspended due to COVID-19 cases very early in the pandemic.

When work resumed, they started with the Living Kidney Donor programme first because both donors

and recipients could self isolate beforehand – obviously not possible with the deceased donor programme. All of the existing donors have been fine throughout the process, and there is now a queue of potential donors.

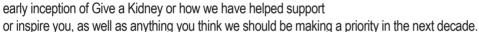
As with all other Transplant Centres, safeguarding will continue to be key as there is too much uncertainty about the availability and efficacy of a vaccine, so that the 'new normal' will be at least as good as the 'old normal'.

Give a Kidney's important role

Give a Kidney's support in restoring public confidence that the transplant community is recovering and continuing to encourage donors to come forward is crucial. It's important to note that a large part of what Give a Kidney does is working with NHSBT and other relevant bodies and perhaps that has been understated in the past. Because of its very particular mission, Give a Kidney is a salient point of contact for NHSBT and there isn't a major meeting or important piece of strategy concerning kidney donations that hasn't involved Give a Kidney.

10 Years of Give a Kidney

2021 will mark ten years since the establishment of Give a Kidney. It's hard to believe how far living donation has travelled in the last decade and how much a part of 'business as usual' non-directed donation now is within transplant centres. As we reflect on the last decade, we'd be keen to hear any of your memories about the



Do drop us a line if you've anything to share or would like to feed in any comments or thoughts. info@giveakidney.org



"The new normal

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New Resolution passed

At their AGM in July, Give a Kidney passed a resolution to change the form of the charitable organisation from an unincorporated association to a Charitable Incoporated Organisation (CIO), and therefore no longer be a 'membership' organisation. This new structure makes it easier to operate as a charity and limits Trustees' liability.

Effective Altruism

Many people who donate a kidney do so because they want to make a positive difference to someone else's life. We've become aware that someone else is less fortunate than ourselves and have taken action to try to do something about this.

We might also be 'altruistic' in our wider lives, whether that is through our choice of work or volunteering, giving of time or money to charitable causes, or simply through our way of being in the world.

With so many worthy and urgent causes appealing for our time, money or skills it can be easy to become overwhelmed and difficult to navigate the impact of the choices we make if we want our time or money to do the most good.

The concept of effective altruism is "a research field which uses high-quality evidence and careful reasoning to work out how to help others as much as possible. It is also a community of people taking these answers seriously, by focusing their efforts on the most promising solutions to the world's most pressing problems."

Essentially, the concept looks at how and where each of us can make the greatest positive impact if we apply knowledge and research to the choices we make.

The website www.effectivealtruism.org has a wealth of information and inspiration, and takes a particular approach to how we might think about prioritising projects which are great in scale, highly neglected or highly solvable to maximise the impact we each make, suggesting three priority areas as alleviating global poverty, improving animal welfare, and trying to influence the long-

term future.

It also has practical suggestions for how we might best contribute time or finance for maximum impact, as well as having links to active local groups, talks and dedicated events and challenges.

> https://www.effectivealtruism.org/articles/ introduction-to-effective-altruism/

