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### Nighttime Climb in Orkney

Old men on the Old Man, to raise awareness of living kidney donation



In September this year, less than two years after a successful kidney donation, I and my good friends Glenn (of Glenn Gordon Mountaineering) and Neil Busby (of Climb Caledonia Ireland) intend to climb the iconic Scottish sea stack, The Old Man of Hoy. At night.

The climb is also special for Glenn as in January 2018 he had a bad climbing accident and was told to give up the sport. Yet less than two years on he is back like me, doing what we love.

The purpose of the climb is to again raise awareness for living kidney donation and show that donating a kidney does not impact the donor's lifestyle. In Scotland we could become the first country to eliminate the waiting list for kidneys - if the number of live donors could increase from 14 per million a year to 33 per million a year. This is not unachievable, but it can only be done through raising awareness and dispelling myths around organ donation.

If you think this venture - scaling the Old Man at night, a trip into the unknown - sounds mad, I'd counter it by saying that with the right information and the right people, the risks are minimal and the benefits are amazing, both for us and for the cause for which we are campaigning: no waiting for want of a kidney.

*Ray Duffy*

## Collaboration was the keyword at this year's annual conference



Give a Kidney's annual conference and AGM was held on Saturday 23rd March in London. The theme was 'collaboration', highlighting that as a small charity we can be most effective where we work with other organisations to influence change.

As a direct result of last year's Conference, and one way that our close collaboration with NHSBT has brought progress, the latter has reviewed and expanded their programme to explore ways for improvement of the altruistic donor experience. A positive experience means subsequent support as an 'ambassador' is much more likely. Others included joint working on the Strategy Implementation Group for the Living Donor Transplantation Strategy 2020, the NHSBT Stakeholder Group, NHSBT Kidney Patient Group and Organ Donation Forum, and the HTA Public Panel. Give a Kidney also took part in various research projects such as the BOUNd Management Committee and Steering Group, 'Key Experiences of Primary Social Groups in Unspecified Kidney Donation' (about to be published in the Journal of Renal Care) and other research.

## Give a Kidney Trustees

The following were confirmed as Trustees:

- John Fletcher, BVMS, Hon FRCVS, PhD
- Paul Gibbs, FRCS (Eng), MD
- Sanjiv Gohil, BA (Hons), Dip Arch RIBA
- Kiran Gupta
- Sara Stacey, RN, Dip Nursing, BSc (Hons)
- Paul van den Bosch, MRCGP
- Robert Wiggins



This year, Give a Kidney recognised three people who have made a real difference to the world of altruistic donation. The first is Lisa Burnapp, Lead Nurse at NHSBT whose support has been absolutely invaluable. Her expertise, inside knowledge of the NHS and of course endless patience and perseverance are enormously appreciated.

We also wanted to recognise Di Franks, whose website [livingkidneydonation.co.uk](http://livingkidneydonation.co.uk) has supported and informed countless people interested in becoming living kidney donors. This she does in her own time and at her own expense.

Finally, Paul Dixon (picture above) who has now signed up over 12,000 people to the Organ Donor Register by volunteering in the foyer at two hospitals in Liverpool. An altruistic donor, he had his organ donor card tattooed on his arm. He says it helps start conversations about organ donation.

## FINANCES

It's difficult to measure success of a campaigning charity in economic terms, but Sanjiv Gohil, Give a Kidney's Treasurer, reported that income exceeded expenditure over the year, reaped from the following sources:

- Donations through Just Giving, MyDonate, CAF and PayPal
- Regular monthly donations
- Several large donations, including one of £5,000 from Toureen Charitable Trust, £7,000 raised by Gabhru Panjab De (GPD) the Bhangra Dancers from Birmingham and further funds raised by Jasie Rai, a kidney patient, as a result of her East Meets West event and Marathon.

## Patient Public Engagement in Action

The Living Donor Kidney Transplant 2020 (LDKT 2020) Public and Patient Engagement (PPE) Workstream, which includes representatives from Give a Kidney, NKF; Kidney Care UK and many others, was launched earlier this year. Knowledge and expertise from donors and recipients has been gathered to identify priorities with regard to issues such as creating a distinct identity for living donation (separate from deceased donation), improving understanding of the living donation process, safeguarding and supporting non-resident donors donating in the UK, and increasing LDKT in communities that are less likely to engage. To address the latter, NHSBT has commissioned the National Black, Asian and Minority Ethnic Transplant Alliance (NBTA) to administer a Living Transplant Initiative for two years, with the aim of increasing engagement with BAME communities.

## Achievements and media coverage over the past year

Give a Kidney's Executive Officer, Jan Shorrock, reported that local press activity had been steady throughout the year. Two major stories were picked up: celebrations in Spring around the 10th anniversary of the first donation in Scotland, which coincided with World Kidney Day, had brought lots of coverage - following which, 15 people came forward to donate. Alex Cole-Hamilton MSP had been particularly helpful with the Scotland campaign. Also, the meeting between non-directed donor Teresa Dobson with her recipient, Joe Salvatore, created lots of interest.

Hearing about other people having donated a kidney to a stranger continues to be the strongest motivation to others to do the same. This was clearly illustrated when a TV programme about organ donation that aired in Belfast, led to 80 people contacting the NHS to offer to donate a kidney to a stranger.

In March, the 1,000th living kidney transplant operation, made possible by a non-directed donor, took place. For the first time, all four UK governments took part in a campaign around living donation for World Kidney Day and new materials and resources which include altruistic donation were developed by NHSBT, with input from Give a Kidney's Executive Officer.

The charity has been involved with a number of conferences and events, including UK Organ Donation Week in Parliament, BTS Living Donor Forum, Charity Conferences, a Joint Living Donation Awareness Event with Kidney Care UK in St Albans, as well as local talks, presentations and stands at events around the country, manned by members. There was also another partnership with the Brandenburg Series for a concert in November.

**Thank you and good luck to David Lee!**



It is with sadness that we say goodbye to David Lee, who joined the steering committee in 2014, and whose work to help establish a business model for the charity has been greatly appreciated. He is returning to his homeland, Hong Kong, and we wish him well.



## Towards a new era in organ donation and transplantation

As I write this, we are in the midst of Organ Donation Week. A key focus for this year is to ensure that everyone is clear about the change in the law for deceased organ donation, which will come in next Spring. You can find all the information that you need on our website at [www.organdonation.nhs.uk/](http://www.organdonation.nhs.uk/). This is a significant change and one that affects everyone, so it is important that people are well informed and that any myths, which inevitably arise at times of change, are dispelled, quickly and accurately.

Give a Kidney has an important role in this -not only in correcting any misconceptions about 'opt-out' but in ensuring that people who might be willing to donate as a non-directed living donor

are not dissuaded from volunteering on the basis that their kidney is no longer needed. Thanks to non-directed donors, the UK living kidney sharing scheme is thriving and benefiting our most difficult to transplant patients. We saw the largest increase in transplants through the scheme last year and the numbers are going up. So, the message is clear- please keep giving to make a difference!

The other focus for NHSBT this year is the development of a new 'Post 2020' Strategy for organ donation and transplantation. From April 2020, living and deceased donation for all organs will be combined in one strategy. NHSBT's role is to engage with the health departments and the wider transplant community to facilitate the development of

the strategy so that it meets the needs of donors, recipients and everyone involved in the organ donation and transplantation programme. A lot of work has been done since the Spring to identify the key themes and a series of stakeholder events are being held over the next couple of months to ensure that people can input their ideas. Make sure that you get involved- let your Trustees and Steering Group members know your views so that they can input them on your behalf.

As always, thank you for all you do to support living donation. For those of you who are interested, latest reports and statistics are available here:

[www.odt.nhs.uk/statistics-and-reports/](http://www.odt.nhs.uk/statistics-and-reports/)

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NHSBT branding specific to living donation, aligned with the 'Yes I donate' imagery, has been introduced and now features on all website materials. Other resources will be updated as they are re-printed. In May, it was agreed that Give a Kidney leaflets would be sent out to transplant centres quarterly instead of just once a year.

### Fundraising service

Earlier this year, BT announced that its fundraising platform *MyDonate* was to close on 30 June. It was the first commission-free service of its kind and for this reason, Give a Kidney's preferred online donation and fundraising platform.

However, *Virgin Money Giving* was quick to respond to the news by dropping its joining fee for new charities for a limited period. There is a 2% fee on donations, but donors have the option to pay that on behalf of the charity. According to the company, since launching the 'Donor Covers Fee' in November 2018, eight in ten donors are choosing to pay the fee on behalf of the charity.

Give a Kidney will be contacting all those who previously made regular payments through *BT MyDonate* to ask them to switch to *Virgin Money Giving*. We apologise for the inconvenience this will cause, but very much hope that they will continue to support the charity.



## INTRODUCING KIRAN GUPTA

Kiran is Give a Kidney's newest Trustee and member of the Steering Group. This is her personal story.



Back in 2011 I signed up to be on the Bone Marrow Registry and a year or so later I saw something about living kidney donation mentioned in some NHS literature. I was already a blood donor and on the organ donor register, and I knew immediately that it was something I should be able to do, and that I wanted to do. I made enquiries about the process, but the need to take some time off work after the operation wasn't possible at the time ... it wasn't until a gap in employment five years later gave me the chance I'd been waiting for and I began the assessment process.

My surgeon was brilliant in every way – understanding my motivations as well as inspiring confidence with regard to the surgical procedure itself. The operation went smoothly; I was in hospital for only a few days, and after about four weeks I felt back to normal.

Donating my kidney really is one of the best things I've done. My only regret is that because of circumstances and timing, I was not part of the paired / pooled donation scheme which would have benefitted more kidney patients.

If I had any advice for someone thinking of donating a kidney, I'd say do your own research so you feel confident that you know what you're doing and what your experience might be like, before and after the surgery. Read through the resources and information on the NHSBT and Give a Kidney websites, and maybe ask them to connect you with another living donor for an informal chat and to offer some support. Consider carefully whether you have the emotional resilience and perseverance needed to get through the lengthy assessment process.

## Give a Kidney – re-evaluating our boundaries

Every so often every organisation should reconsider how to best use its available resources to meet its ultimate goals. Since Give a Kidney was founded, its aim has been to increase the number of non-directed (altruistic) living kidney donations (NDALD) by raising awareness, supporting future and past donors and influencing change all in an effort to move ever closer to our vision of “no waiting for a transplant for want of a kidney”. Strictly speaking, NDALD is where a donor gives anonymously to a complete stranger, with NHSBT deciding to whom the donor’s kidney is given. Two developments are now blurring the lines of what were quite clear boundaries of our work.

The first is the success of the living kidney sharing scheme. The dynamics of donating to someone you are emotionally attached to is quite different from those of an “altruistic” donor, where there is no pre-existing relationship between donor and recipient. So in the case of the sharing scheme, where a living donor donates to someone they don’t know on the understanding that another living donor is donating to their loved one, are those donors directed or non-directed donors? Should the charity be looking to raise awareness of the sharing scheme amongst those with an emotional connection with someone on the transplant list and should we support these sharing scheme donors?

Secondly, with the increase in the use of social media by those looking for a suitable living kidney donor, we now have directed (altruistic) living donors (DALD) where there is no prior emotional relationship between donor and recipient, but the donor is specifying to whom they are willing to donate. Again, is Give a Kidney looking to support these donors? And, as we rely so much on living donor coordinators in the transplant units to support non-directed donors, should we get more involved in helping to create a ‘best practice’ guide to ensure that social media campaigns are safe for both the potential donors and the recipient, as well as avoiding or reducing any risk of inefficiencies on the transplant unit when confronted with a list of possible donors?

This thinking could be taken a step further. It is clear to many of us that those directed living donors (DLD) who donate to someone with whom they have a pre-existing emotional relationship do not have an organised support network to turn to. Arguably these donors have the most complex ongoing support needs. Should the expertise Give a Kidney has developed in raising awareness of living donation generally and supporting future and past donors be utilised to fill this void by reaching out to a wider living donation audience, and if so, how far?

These are questions that are on the minds of a number of us tasked with steering the future course of Give a Kidney. We would welcome the views of our members and others who have a vested interest in our future. If you would like to comment, seek clarification or want further information, please contact us at [info@giveakidney.org](mailto:info@giveakidney.org)

*Bob Wiggins, Chair, Give a Kidney*

### Unspecified Kidney Donation in the UK: Insights from the BOUNd study

BOUnD is a five year, nationwide, prospective study, using mixed methods of collecting data from donors - both specified (SKD) and unspecified / altruistic (UKD) and transplant professionals. It aims to discover whether variation in transplant professionals’ practice and attitudes are preventing some unspecified donations; whether psychosocial and physical outcomes after UKD are equivalent to those after SKD and to determine the economic benefits of UKD: what is an altruistic donor worth?

Interim analysis shows that there is no longer a significant difference in age between Unspecified Kidney Donors (UKD) and Specified Kidney Donors (SKD); the former are getting younger (average age is now 48.5 years).

Disputing claims by some that religion is a motivating factor, there is no evidence that UKDs are more religious or motivated by religion.

Other findings are that UKDs take significantly longer to donate (over twice as long as SKDs), in part due to the mental health assessment that UKDs have to undergo; plus there is more likely to be a lag with SKDs due to recipient issues. The volume of transplants undertaken at Centres does not appear to have an impact on time it takes to complete the donation process.

UKDs display more consistent altruistic behaviours: they are more likely to be blood donors, bone marrow registered, organ donor registered and to donate to charity or do voluntary work.

*“The BOUNd study uses the EU terminology of specified and unspecified donation in place of the UK terminology of directed and non-directed”*



It’s over a year since Chris Burns-Cox, our founding trustee, died in June last year. He was a tireless campaigner, a great believer in the good in people and his boundless enthusiasm is greatly missed. His thinking continues to inspire our work as a charity:

*If we campaign effectively enough for this, the days of suffering and dying on a kidney transplant waiting list will be over. Humans will again show that we can not only torture, exploit and kill but, amazingly, save each other.*



World Kidney Day on 14 March saw a huge increase in traffic to NHSBT’s website, with total visits up 78% on the previous year and downloading materials up 35% on the previous year. There were 3494 visits to the NHSBT website during that week (11th -17th March 2019).

Online activity on the Give a Kidney site also continues to perform well, with 130,000 visitors to our website over the year, and 250,000 page views. 90% were new visitors.

On social media, we now have over 2,500 Facebook ‘friends’ and over 1,500 twitter followers. Posts now regularly reach over 10,000 people.

### Contact us

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