



Give a Kidney – one's enough
Annual General Meeting & Conference
Saturday 25th March 2017

Welcome to the AGM

Bob Wiggins (BW), the charity's Chair, welcomed guests to the meeting and thanked all for attending. Particular thanks go to Sanjiv Gohil for arranging the meeting venue. Not only were the offices perfect for our needs, but the charity was able to save a considerable sum on venue hire and catering as a result.

Chair's Report

BW reminded guests that our vision is 'no waiting for a transplant for want of a kidney'. We do this through raising awareness of altruistic living donation the need for more donors to come forward, collaborating with other organisations to achieve our aims and to support prospective and past altruistic living donors. 2016 saw an unprecedented amount of media coverage relating to altruistic donation. Supporting donors as they go through the process and email traffic to the website has also increased.

We would like to do more, but find ourselves constricted by a lack of resources.

We have done some fundraising, for example the Brandenburg concert in November that raised over £1,000 and an appeal to trusts in May. We have also approached some potential corporate sponsors. We still have a small audience who are funding the charity and need to find ways to extend that reach.

Regular monthly contributions from any members who feel able would be a great help.

Executive Officer's Report

2016 saw an enormous amount of media coverage, social media, events, fundraising and the forging of new partnerships.

The campaign around the 500th donation, a joint campaign with NHSBT, had a reach of 18m from media alone, much more if social media is included.

More recently, the Kidney Shaped Love campaign around Valentine's Day was NHSBT's first living donation campaign and there were also other significant living donation stories through the course of the year including a kidney from a living donor turning 101 years old (donated by a mother, to her daughter) and an 11 year old boy in need of a kidney, but with just one in 650,000 chance of finding a match. Subsequently a suitably matched stranger offered him a kidney on Facebook.

On Facebook the charity now has 1,800 followers and 974 on Twitter, although significant moderation is still required, with requests to sell kidneys common. We enjoyed our first viral post, reaching 170,000 users, when Celia Kent celebrated her 101 donations – 100 pints of blood and a kidney!

Traffic to our website is up 45% on 2015, with 136,975 visitors, 84% of these new. The peak was around the 500th donation campaign.

We've been represented at events including the Transplant Games in Liverpool, the Brandenburg Choral Concert, Conferences (ELPAT, EDTCO, BTS and HTA) and many other meetings.

We are very grateful to all those who organised fundraising and events during 2016.

We have worked to establish and develop effective partnerships, in particular with NHSBT where we collaborated on their new website and on updated materials including non-directed living donation leaflets available in 10 static blood donor clinics and ensuring that our message on living donation was included in future media campaigns.

Next we will be focusing on the 10th anniversary of the first donation in the UK this Summer and subsequently at each transplant centre.

Treasurer's Report

In 2016, the charity spent £30,278 with income of just £16,753. Our savings account balance has reduced from £30,000 to £15,888.

Costs can be broken down as follows: Administration £9,285; PR & media £11,956 and travel £1,836. Miscellaneous costs in addition include £3,056 for venue hire, £3,345 for newsletter and other printing and £528 in charity fees and PO Box costs.

The accounts for 2016 will be available on our website in due course.

There is a clear need for an increase in income if we are to continue the work we have begun.

Confirmation of Trustees

During the course of 2016, Roger Corke stepped down as a Trustee.

The remaining six Trustees (Chris Burns-Cox, Paul Gibbs, Sanjiv Gohil, Sara Stacey, Paul van den Bosch, Bob Wiggins) will all continue as Trustees.

Two new Trustees were appointed by acclamation: John Fletcher and Gill Owens. John is a deer farmer in Fife and donated a kidney altruistically eight years ago. He has been instrumental in setting up Give a Kidney Scotland with fellow Scots including Colin McLachlan and Chris Jones. Gill is a Psychologist and Senior Lecturer at Teeside University. She is also a non-directed kidney donor.

Chair's Summary

We understand the importance of the media in spreading our message, as so many who step forward do so because they have seen something in the press about non-directed donation. Nowadays it's not such big news, so we have to find new ways to interest the press. Every donor makes a huge impact not only on that one recipient, but also on the many people around them.

Events cost money but we do need them to engage with the public effectively. Three people came forward at the Brandenburg concert with an interest in learning more about donation.

BW made guests aware that travel mentioned by the Treasurer is almost all within the UK, for example SC members attending meetings in Scotland and London, with very little abroad. Virtually all the international travel was covered through sponsorship.

It was suggested from the floor that another area we should begin to look at is Legacy Fundraising, although as such a young charity this won't be an immediate source of income.

We might also look at our expenses and see if some of those can be shared with other groups working towards the same aims, for example NHSBT, or if we can find a sponsor.

LB mentioned charity vouchers which can be bought as a gift.

Fiona Loud of BKPA offered congratulations on the charity's success to date and looks forward to working together in the future towards our common aim of helping kidney patients.

John Fletcher thanked the charity for allowing Give a Kidney Scotland to become affiliated and welcomes any suggestions guests might have. The newsletter is very helpful - thanks as always to Viv Calderbank for this. The Give a Kidney website is another useful shared resource, with contacts and links and we are grateful to Jim Fatah for hosting this and Steve Kerner from Curious Road Design for the design.

Paul Gibbs pointed out that 600 altruistic living kidney donations will save the NHS £12m to 15m per year over the cost of dialysis, for every year the kidney works after the first year, when the costs are comparable.

We need to articulate better why there needs to be more focus on non-directed living (altruistic) donation and thereby generate the will to make NHS England commissioners take note. We can do this more effectively by continuing to raise our profile and credibility. The 2020 Strategy saw living donation appear for the first time, which is a clear sign of progress.

Conference

Lisa Burnapp: Where we are now

Thanks to work in recent years, there is real momentum now and change is happening.

In the 10 years from 2006 to 2016, there has been a 15% decrease in waiting lists, a 48% increase in transplants (all organs) and a 69% increase in deceased organ donors. The waiting list is consistently going down and the number of transplants annually going up. Living donors now make up 44% of all donors.

Overall, in conjunction with the strategy for deceased donation, the 2020 Strategy for living donor kidney transplantation aims to achieve:

- The best outcome for every donor and recipient
- More successful transplants for more people
- The right transplant at the right time
- The most of every transplant opportunity, every time
- Equity of access to transplantation

UK living donor kidney transplants, as calculated per million populations, are behind only The Netherlands, Denmark and USA. As in the UK, leading countries are seeing a drop in living donor numbers, a trend we are working to address.

There are funding constraints throughout the NHS but NHSBT continues to work with Health Departments and NHS England to maintain the profile of living organ donation across all four UK countries.

The 10 year Living Donor Kidney Transplant (LDKT) centre specific activity report was published in September 2016 and will be published annually from now on. Donors are all invited for follow-up, with electronic reporting and a UK registry established.

Efforts are being made to improve access to LDKT. In the past year, NHSBT has engaged with the clinical community with shared learning events in transplant and referring centres using centre-specific information to learn from best practice and achieve consistency across the UK programme. As well as a press release around the 500th non-directed donation, NHSBT ran its first publicity campaign dedicated to living donation in the run up to Valentine's Day this year- 'Kidney-Shaped love', which created significant interest from patients and the public. NHSBT donor and recipient resources have been revised and improved, including access to on-line resources via the website, pop-up banners in transplant and referring centres and a pilot of leaflets in blood donor centres. Online films and an online register of interest for non-directed donors, hosted by NHSBT will be launched in April 2017.

The UK Living Kidney Sharing Schemes aim to make the best use of all kidneys donated from living donors into the 'pool'. The aim is to ensure that 75% of non-directed donors donate into a chain rather than direct to the waiting list to increase the number of transplant opportunities per donation. Compatible pairs are also being encouraged to donate into the sharing schemes- so that they might find a better age or tissue type match for example- and create more opportunities for themselves and other patients waiting for a transplant in the paired/pooled programme.

A unique peer volunteer, home education pilot, run in collaboration with *Kidney Research UK* and *Gift of Living Donation (GOLD)* to encourage engagement in living donor kidney transplantation from black and Asian communities is due to complete at the end of March and will be reported soon. Emerging research from the multi-centre ATTOM study in the UK, shows that patients who are young, white, married and from higher socio-economic groups are considerably more likely to be transplanted from a living donor, so there is some way to go before equity of access can be achieved.

Highlights for 2016 / 2017 include:

- Acceptance Choice and Empowerment (ACE), a collaborative project between NHSBT, Kidney Research UK and GOLD. Only 1% of donors come from the BAME community and this project, among others, aims to address that imbalance, in this instance in the African and Caribbean communities in North and West London. Dela Idowu is a home education champion, running this UK pilot with volunteers to educate, empower, engage and enlist living donors.
- NHSBT has made considerable progress in terms of campaigns and resources around living donation, in particular the website, which, in response to requests from donors and recipients, has been developed to provide the 'go to' website for living donation.
- Leaflets on living kidney donation are now in 10 static blood donation centres. Response will be evaluated to inform roll-out in more centres in the coming year.

- The Kidney Shaped Love video had 117,130 views and 3,410 reactions. There were 25,385 web visits, an increase of 604% on the previous four day period.

LB acknowledged team work at NHSBT, in particular Sally Johnson, John Forsythe and the communications /campaigns teams who have supported the strategic work around living donation and the recent campaigns. Also the many groups who have collaborated, including particular thanks to Give a Kidney's JS and BW.

Lynsey Williams: BOUnD – qualitative project update, initial findings and the future directions

The BOUnD study: Understanding Barriers & Outcomes of Unspecified Kidney Donation (UKD) is being undertaken at Plymouth University's School of Psychology.

Today's presentation looks at the barriers and enablers for completion or withdrawal from the donation process. Previous studies have not included donors who have withdrawn from the process.

10 NDADs participated in two focus groups; five had completed the donation process and five had withdrawn.

The focus group data was coded and sorted into themes, with some themes arising more frequently in one group than the other.

Work / time: The withdrawn donor group was much more likely to raise issues relating to the time commitment and impact on work of the donation process. Both groups mentioned difficulties experienced due to the numbers of hospital visits and lengthiness of the donation 'work up' process, but it was discussed in more length and with more frequency in the withdrawn group. The withdrawn group also drew attention to the negative implications of the post op recovery period, but this topic was absent from the completed group discussion.

Getting together: The withdrawn group raised this theme more often, indicating that 'getting together' is more meaningful for the withdrawn donors. A contrast was the completed donor group emphasis on shared experiences amongst themselves – with no mention of withdrawn donors as a group to get together with. Conversely, in the withdrawn donor group the desirability of meeting completed donors came through strongly.

Relationships with other donor groups: The completed donor group had considerably more to say about relationships with other donor groups and the recipients of kidneys than the withdrawn donor group. This theme reflects three aspects of relationships with other donor groups or recipients: (1) how they position themselves in relation to other donors; (2) relationships with recipients, especially in relation to anonymity; and (3) ethical and emotional aspects of being a UK donor.

Barriers: Both groups showed awareness of factors that would undermine the motivation to donate a kidney. In the withdrawn group barriers were more clearly described, showing normative assessment of UKD as a surprising and unique thing to do. This contrasted with accounts from the completed donor group, which normalised the experience and also demonstrated working through difficulties.

Family barriers and enablers: The withdrawn group was more likely to talk about problems and perceptions relating to family views. The completed group demonstrate empathy about the risks for family members and talk about their support, contrasting with the withdrawn donor group, who frame the role of family

members as risky to their progression to donation; they were less likely to discuss donation with family members, for example thinking they might do so only after passing the necessary tests.

Professionals: The completed group report personal and emotionally connected relationships with staff. 'Professionalism' appears frequently. Conversely the withdrawn group express their views about professionals in an 'us and them' context; talk centres more on the actions of staff such as 'well organised'.

Publicity: Both donor groups stress that the *possibility* of donating a kidney to an unspecified recipient is not well known. The withdrawn group emphasised education in a more formal context, for example in schools, while the completed group favoured promotion centred on personal stories, including recipients' experiences and stressing their own experience and reasoning as a basis for effective publicity. Conversely the use of recipients as an effective means of publicising UKD was absent in the withdrawn group, which showed a more abstracted and less personally involved appreciation of the publicity process.

Conclusion: This study is the first to compare the different experiences of withdrawn and completed altruistic kidney donors, allowing a light to be shone on the factors that impact on the donation process. Significant differences were seen in how experiences are perceived. For those who have continued through the donation process to completion, their experience is expressed as 'complete'. They also conceptualise themselves as a defined group with opposing dimensions of the common themes. In contrast the withdrawn donor group reference the incomplete nature of their experience and undertake comprehensive accounting for this, referencing completed donors in their talk as a counterpart to the withdrawn experience.

The research project continues as other aspects of unspecified kidney donation are investigated.

Lisa Burnapp: Chains, choices & possible obstacles

Anecdotally, almost all non-directed (altruistic) living kidney donors choose to donate into a chain in principle at the start of the process, yet by the end the majority donate direct to the waiting list. This means opportunities are being lost and LB would like to understand what is happening within the process to lead to this outcome.

One reason may be that donors don't want to wait; the process is slow, in particular the wait for mental health/specialist assessments, so they don't want to wait any longer by the time their donor assessment is complete. Several people in a chain means a greater risk of delay.

LB now tells donors she sees at the start of the process what should happen and within what time scales, in an effort to manage expectations. She asks donors to chase if timeframes slip. PG reported that, in his centre, there are summer bottlenecks, with donors choosing those months to recuperate and so it is difficult to accommodate all the necessary operations at one time of year.

Some donors will always donate direct to the waiting list if they prove to be a match for a 'high priority' recipient ie. someone with very low likelihood of finding a suitably matched donor.

Fiona Loud explained that she is aware, through the BKPA's closed Facebook group, that knowledge around kidney donation varies greatly so information and education is helpful.

PG assured all that there is capacity to accept living donor referrals so people should not be discouraged from coming forward.

Carol Jennings: Independent Assessor with HTA

She stressed that independence is key to her role, as she is there to protect the donor, ensuring that they are donating of their own free will and with no evidence of coercion or reward and have the capacity to understand what is involved and agree to removal of their kidney. The Human Tissue Act states that no organ can be removed without a special dispensation, i.e. valid consent. Transplant Units have a legal obligation to comply with this Act. IAs, who come from a wide range of backgrounds, need to be confident that the kidney is given voluntarily and of course no offer of payment, other than expenses, has been made. Questions to be answered include why they have chosen to do this, so as to assess motivation.

Potential donors need to be aware that publicity in advance of donation not only threatens anonymity, but any kind of film or other media might be seen as a reward or encouragement and may also make it difficult for the donor to change their mind about giving a kidney.

This interview is usually undertaken towards the end of their investigations and preparation for transplant (sometimes referred to as Work Up), sometimes even after a date for the operation has been set. Donors of course have the right to change their mind at any point in the Work Up process.

RH: A recipient's perspective

RH is an Advocate for charity Live Life Give Life, a charity which aims to encourage more people to register as organ donors and raise awareness and public acceptance of organ donation through awareness campaigns, events and activities.

In 2001, RH was diagnosed with a rare genetic condition, Alport Syndrome. In 2011 his condition suddenly worsened and he started dialysis, which meant being attached to a dialysis machine for eight hours every night. He also went on the transplant waiting list.

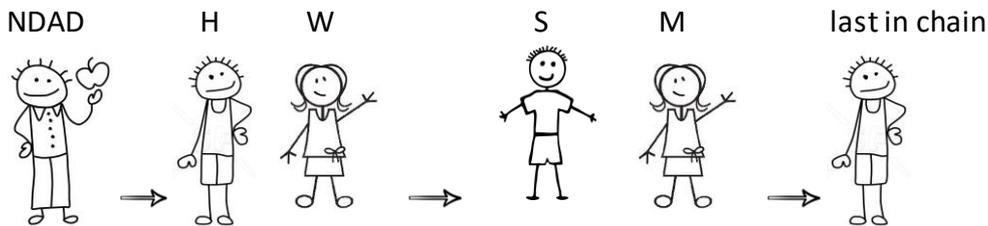
Family members were tested and for various reasons, decided they were unable to donate. However, his cousin came forward and was found to be a match and in 2013 successfully donated a kidney to RH.

RH related his experience of being on dialysis. Although he continued to work full time, he was very tied to the dialysis machine. He was also aware that the call offering a kidney could come at any time, so could never travel too far from home. His chronic illness and resulting stress also had an impact on his partner and her way of life.

His life has completely changed since receiving his new kidney. He enjoys being able to travel abroad and in September 2014, was overjoyed when his daughter Olivia was born.

Paul Gibbs: Moral Dilemma

PG explained that a short chain was arranged as follows: a non-directed (altruistic) donor (NDAD) donating to a man, whose wife then donates to a son, whose mother then donates to another recipient in need.



The night before, the surgeon was told that the husband couldn't receive the kidney from the NDAD as planned. He'd first need two weeks of drugs in preparation.

Options: should the whole chain delay for two weeks, or should the rest continue – given that the second recipient (the son) had gone through two weeks of preparation? The first operation was re-scheduled for two weeks' time, but the others went ahead.

Two weeks later the NDAD went back to hospital, only to be told that again the recipient was not in a position to accept the kidney. The NDAD was reluctant to reschedule his time off work for recuperation once again. Should he wait again for the recipient to be well enough, or should he now offer direct to the waiting list, given the uncertainty around when / if ever the recipient would be well enough? The NDAD decided to donate the next day direct to the waiting list. In the end the recipient was a six-year-old, whose family was of course very happy.

Five months later, the first recipient (husband) is still not fit enough to receive a kidney. Meanwhile his wife has donated one of her kidneys so that her husband could benefit.

This led to discussion among the team and an agreed policy that when he is well enough, the husband will be prioritised, although not above paediatric or difficult to match patients. This is now the case for all those who have been living donors and who find themselves in need of an organ.

To clarify, waiting list priorities as follows:

1. Children
2. highly sensitised (difficult to match)
3. favourably matched (2 or 3/6) then
4. everyone else.

There are other factors, including age differential, time spent waiting and blood group that are all taken into consideration. Surgeons decline around 35% of organ offers in the hope of a better match and outcome.

Summary and close

BW commented on the 101-year-old kidney: donated by a mother to her daughter, it lived on beyond the life of its original owner. Certainly something to celebrate.

LB let guests know about a series of three children's books by Anita and Simon Howell. Titles are *K is for Kidney Transplant*, *H is for Haemodialysis* and *P is for Peritoneal Dialysis*. They're available on Amazon.

The meeting closed, with renewed thanks to all for their interest and support of the charity.

Speakers

Bob Wiggins is an independent corporate and public sector turnaround professional and the charity's Chair

Jan Shorrocks is Executive Officer for Give a Kidney and a member of the Steering Committee

Sanjiv Gohil is a Chartered Architect and Trustee and Treasurer of Give a Kidney

Lisa Burnapp is Lead Nurse, Living Donation, Organ Donation and Transplantation, NHS Blood and Transplant and Consultant Nurse, Living Donor Kidney Transplantation, Guy's & St. Thomas' NHS Foundation Trust and a member of the Steering Committee for Give a Kidney

Lynsey Williams is a researcher working on the BOUnD Project at the University of Plymouth

Carol Jennings has previously worked as a nurse and now works as an Independent Assessor

RH is an Advocate for charity Live Life Give Life and a kidney recipient

Paul Gibbs is a vascular and renal transplant surgeon in Portsmouth Hospitals NHS Trust, where he is Clinical Director of the Renal Transplant Programme and Clinical Lead for Vascular Access. He is also a founding Trustee of Give a Kidney.