Give a Kidney – one's enough AGM & Conference
DoubleTree by Hilton London West End, Southampton Row, London WC1B 4BH

Saturday 18th January 2014, 09.30am to 3.30pm

Welcome!

Chair Chris Burns-Cox welcomed members and thanked all for attending.

The Chair's Report was tabled and CBC talked members through progress over the past year. He is particularly pleased to see numbers of altruistic numbers continuing to rise, despite early predictions that the movement would be short-lived.

Also tabled with the Chair's Report was an Activity Report on the website and social media, kindly produced by Fred Kavalier. The website continues to be a useful resource for anyone interested in altruistic donation. There followed a pie chart showing breakdown of the charity's membership and a report from Gill Buckley who set up Give a Kidney NZ.

Trustees were approved as follows: Chris Burns-Cox (Chair), Paul Gibbs, Sanjiv Gohil (Hon Treasurer), David Hemmings, Sara Stacey, Paul van den Bosch. All Trustees are automatically members of the Steering Committee, where they are joined by advisers Lisa Burnapp, Suzanna den Dulk, Adnan Sharif and Jan Shorrock.

A query was raised as to whether we should campaign for England to join Wales as an 'opt out' country. CBC explained that we are set up to promote altruistic donation, which is not the same thing, but we can use the discussion as an opportunity to remind people that 'you don't have to die to donate'.

Treasurer's report

Sanjiv Gohil, Hon Treasurer, explained that our expenses are low, with just Suzanna den Dulk (Administrator) and Jan Shorrock (PR Officer) employed on an hourly rate. Other expenditure chiefly relates to printing and organising the AGM and conferences, which in 2014 will be reduced to one conference.

Income was £12,091, while expenditure was £17,345 and we retain £31,500 in a savings account.

Very many thanks (to name but a few) are due to David Rang, Robert Wiggins, Willie and Kate Gilbertson-Hall and Phil and Liz Hughes, for fundraising online through Just Giving and of course all of those donating with Charity Choice. Also to LeRoy Shepherd with the Little Britain Lodge and Jasie Rai with the Sikh community of Swindon, who raised considerable funds to start off 2014 in a very positive way for the charity. Also to Paul Dixon who raised £270 for Give a Kidney and presented this at the AGM. Indeed, a big thank you for every single donation, big and small, that supporters of our charity have raised.

SG closed by assuring supporters that the charity will make good use of every penny raised.

Lisa Burnapp
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

What has happened with altruistic donation since we last met, in June 2013?

NHSBT's UK Strategy for Living Donor Kidney Transplantation comes to an end in March 2014. In 2010, the strategic objective was to "promote increases in living donation to match the best international benchmarks within comparable funding systems". The aims were to:

- increase numbers of transplants without compromising donor safety
- increase pre-emptive transplantation and equity of access
- develop the National Living Donor Kidney Sharing Schemes (NLDKSS)

Work is now ongoing to ensure that resources are in the right place with a strategy to take us to 2020. Philosophy, culture and communications all contribute to our ability to increase living kidney donation. National Living Donor Kidney Sharing Schemes, where altruistic donors play an important role in contributing to altruistic donor chains, maximise transplant opportunities for all recipients. Supporting the development of the Scheme will be a key priority for the 2020 Strategy.

The aim now is to have a timeframe of eight weeks from identifying a match to the transplant operation but average timeframe is often more than three months. Not all units currently have the required capacity; donors want dates to fit in with their holidays; Portsmouth is already booked until April. This is useful information to take to commissioners: a faster turnaround is good for patients, donors and for the health economy. However it is human resource intensive, a system which therefore takes time to develop and improve and there are limits to how fast things can change. It requires a cultural shift, with centre variations in capacity and capability.

NHS BT plans two national publicity drives annually, where they will work with Jan Shorrock, Give a Kidney's Press Officer. This year we will celebrate the 250th altruistic donor (although that milestone has already passed, we need to leave time after the operation for recovery).

The mean altruistic donor age is 54 years (range 20 – 85), with 55% being male. The average time between notification and donation is currently 51 days (range 0-224)

The mean recipient age is 47 years (range 3-76), with 54% being male and the average waiting time 40 months.

The key strategic objective that is proposed for the future is to match world class performance in living donor kidney transplantation within the UK, with key themes being:

- Increase LDKT activity for both adult and paediatric recipients, ensuring that donor safety and welfare is consistently sustained through best clinical practice.
- Maximise patient benefit by ensuring that all suitable recipients have equity of access to LDKT and that the principle of 'transplant first' is embedded in best clinical practice.

- Maximise the opportunities for suitable donors and recipients to contribute to and benefit from the shared living donor pool by ensuring that the National Living Donor Kidney Sharing Schemes (NLDKSS) are both clinically and cost effective.

Numbers of living donors in the UK are high compared with other European countries but there is still work to do to match the best in Europe at 26 per million population (currently 18.5 pmp). In order to achieve this, we need to:

- Deliver state of the art donor care
- Influence effective commissioning across the UK
- Develop capacity and infrastructure to maximise transplant benefit through the living donor sharing schemes
- Think 'transplant first'; raise the profile of LDKT
- Minimise variances across the UK

As more patients are being transplanted and outcomes are more successful, the waiting list should decrease. Kidneys are lasting much longer, so it is taking longer for those patients to come back onto the waiting list; more deceased donor kidneys are available; immuno suppression is more effective; all steps of the process are improving. Although the incidence of kidney failure is increasing due to lifestyle choices and people living longer, kidney disease is being detected earlier and managed better. Patient who may not have previously been considered medically suitable for a transplant are now being offered that opportunity.

LB reiterated that it's important to manage the expectations of potential altruistic donors. The process takes time. Time is extended if the donor opts in to a chain there is a quarterly run so they may have to wait to join a chain and for this reason some prefer to donate to the waiting list instead.

Jim Fatah suggested Give a Kidney members write to their MP to explain the money saving aspect of altruistic donation. LB agreed to supply the relevant facts to inform this.

Another suggestion was to advertise altruistic kidney donation in blood donor units, as blood donors have already shown an altruistic bent. LB is working on this; there have been concerns about staff on blood donation sessions having to deal with enquiries that need to be addressed.

Jan Shorrock has contacted The Anthony Nolan Trust to see if we might contact bone marrow donors who have passed the age when they are able to donate bone marrow.

Paul Gibbs
Consultant Vascular and Renal Transplant Surgeon at Portsmouth Hospitals NHS Trust

Deceased donor transplantation

PG explained to members the process of deceased donor transplantation. It takes approximately 24 hours for a deceased donor to go from identification as a potential donor to transplant operation. 2,500 deceased donor transplants take place every year, some donating up to eight organs.

The process is as follows:

A patient who has a head injury or is a stroke victim (for example) is taken to the Intensive Care Unit (ICU). Very quickly, 30 - 40 people have been involved in the patient's care, from the emergency crew, x-ray crew, lab technicians for blood tests, porters etc. The cost per 24 hours on ICU is about £2,500 / day / person.

Most of those patients who die at this stage are not able to donate, because the most common cause of death is multi-organ failure. Neuro-intensive units however have a higher rate of patients with organs being suitable for transplant.

If the patient is dying, there is then a discussion with relatives as to whether or not their organs can be donated. If they are on the donor register, 80 - 90% proceed to donate (if suitable donors) whereas if they are NOT on the register, 40 - 50% go on to donate.

Specialist Nurses for Organ Donation (SNODS) are called, initially assessing the potential donor over the phone. If the candidate seems likely, a more thorough assessment begins, looking into their medical records. By this stage, six to eight hours have passed. If the family has given the go-ahead, the SNOD will talk to the coroner. This is routine but especially true if the police are involved if the death is in any way suspicious such as an RTA.

The next step is to 'type' the donor with a blood test at one of 15-20 labs across the country. This is to discover the tissue type and get a genetic fingerprint.

Different centres are now offered the organs and teams will arrive from one of the seven retrieval centres, performing more invasive tests and ensuring that organ function is maximised. There are five tiers and seven scoring levels following the principle of 'equity of access'. Genetic match and time on the waiting list score the highest points to ensure that people receive the best matched kidneys and to avoid people waiting too long. Paediatric patients are prioritised over adults. For adults nobody should wait longer than anyone else, the average wait being three years. You also win 'points' for a rarer genetic match and/or if you are a type for whom it's hard to find a suitable organ.

Now 14-16 hours down the line, the relevant units are called, generally in the middle of the night! Most suitable donors are in their 50's and 60s, the upper limit is generally 85. The recipient is also contacted and subjected to a battery of tests. The retrieval teams proceed with surgery to obtain the organs and then they are dispatched to the transplanting centres. Up to 200 or so kidneys annually are not used as things go wrong in the process, or an issue is discovered when the kidney is extracted.

A cross match is when the compatibility between a recipients blood and the donor's kidney is checked. The immune system can see the kidney as foreign and shut it down. Patients on the waiting list are checked every three months to establish that they are clear of antibodies so that when an organ becomes available the cross match is not necessary - a "virtual crossmatch".

The transplant can then take place.

Altruistic donors also have to go through these tests, just not as quickly. In addition there is a psychological test for altruistic donors.

45 minutes after death, the kidney can't be donated if death occurs outside the ICU where the organs can't be looked after.

In the 80s, 50% of kidneys lasted 10 to15 years. Now the prediction is nearer 21 years, but living donors' kidneys last longer with 50% lasting 25 to 30 years in the latest predictions.

PR Opportunities for Give a Kidney
Jan Shorrock, PR Officer, Give a Kidney

JS explained that she is an altruistic donor who came across Give a Kidney's website and got in touch. She was told the charity was looking for a PR Officer and applied for the post. She has worked in marketing and PR almost exclusively in the non-profit sector for over 15 years and looks forward to raising the profile of altruistic donors.

A show of hands revealed that about two thirds of altruistic donors in the room were influenced by seeing or hearing a media story about an altruistic donor, so it really is a powerful way to bring about change and increase numbers of altruistic donors.

PR opportunities include: traditional media (TV, newspapers etc.); web and social media (including facebook and twitter); talks, conferences and networking; advocacy and lobbying. Give a Kidney is part of the jigsaw, part of living kidney donation, which is part of organ donation and JS will be working closely with NHS BT.

Altruistic donors are the best advocates, helping plant seeds. Surprisingly donor stories have been found to influence more than recipient's stories. Some are hesitant to share their personal stories, felling that it's showing off, but donors should feel proud, the press is interested and sharing is extremely helpful! JS thanked all those who have so far returned their media forms to her, detailing something of their own experience and letting JS know that they are willing to help. In particular she hopes to complement national coverage led by NHS BT with local stories.

JS will also be working on the website, adding to existing content where possible. She asked members please to interact where possible, because by 'liking' on facebook and 'retweeting' we can increase our reach.

JS also thanked those who have organised events for the charity recently. These not only raise vital funds, but also raise awareness of the charity. JS is always happy to help publicise events. Also to bear in mind that places of worship, alumni magazines, friends and family can all be made aware. Suzanna has charity wristbands she can send to members and these make good talking points. Do please encourage your friends to retweet and like us on facebook.

Specific stories in the pipeline include a feature by Christian Brazier on donors who've met their recipients and Alan Titchmarsh looking for donors who will be publicly thanked. She will also investigate the Evangelical Alliance to see if they are a group we can work with.

Alexis Clarke & Hannah Maple - Latest research into altruistic kidney donation

Alexis (University of Plymouth) is a clinical psychologist and Hannah (Guy's Hospital, London) is a surgeon, currently studying for a Phd in Psychology and writing a thesis on the psychology of living donation. The two are now working together on research into altruistic donation.

In the UK we are developing an understanding of the experience of donors, their motivations and outcomes. Support of family members for example is important to the success of altruistic donation. AC and the team in Plymouth are researching 'Understanding the barriers and enablers to donation in a social group context.'

They are looking at the outcomes and benefits of the unspecified living kidney donation programme in the UK, with aspects including:

- Economics – the effect on the NHS, on donors and on society
- What happens in transplant centres and how it affects donation
- Following donors through the process – and those who pull out before donating

Some interesting facts include:

- In some centres up to 40% of potential donors have been reported to be turned down on psychological grounds. This does not necessarily mean a psychiatric diagnosis was made in all cases but that a psychological or social issue was identified. These papers report small figures from early on in the altruistic donor programme and may not reflect what is happening today. We need to understand what criteria are being used to judge; are questions standardised?
- 75-80% of those who initially call their local transplant co-ordinator do not proceed to surgery. Many who pull out early do so on health related grounds, but we need to understand what happens to the rest. Even in directed donation, the numbers that pull out are still high. Could it be problems with an employer? Or disapproving family members?
- This is still a relatively new process, with surgeons initially reluctant to remove a kidney from a healthy person. The scrutiny is therefore intense. The UK is one of the top three countries in the world for altruistic donation, behind only USA and the Netherlands.
- A UK prospective study is only feasible at this stage due to the increased yearly numbers. AC and HM intend to secure funding for a comprehensive five year study which would commence in January 2015.

Do contact Alexis Alexis.Clarke@nhs.net or Hannah HannahMaple@doctors.org.uk if you would like information on past research or if you would like to help with their research in future.

Adnan Sharif - Organ donation issues amongst the BAME population

Adnan Sharif is Consultant Nephrologist, Queen Elizabeth Hospital, Birmingham

Regionally the West Midlands has the biggest waiting list in the UK and their patients wait longer than the three-year average. A NKF report in 2011 sought ways to improve donation

rates within the BAME community and the National BAME Transplantation Alliance brought various groups together under one umbrella to examine the issues.

UK population is 64m, with 12.8% BAME. By 2015 it's predicted this will rise to 20%.

Birmingham has a population of about 1m, 42% are BAME (7.2 black, 22.5% S Asian), whereas the London population is over 8m, with 40.2% BAME (20.9% S Asian, 15.6% black)

Of the UK population in general, the BAME community make up 24% of the waiting list for organs. Just 3.4% are registered as organ donors (where ethnicity is known: most register through DVLA where ethnicity is not recorded). The BAME community make up 4.2% of actual deceased donors, with the family refusal rate being twice as high.

Various factors are recognised as contributing to the low numbers of BAME organ donors:

- Religion
- Socio-cultural
- Family
- Distrust of the health service
- Language barriers – SNODS are rarely BAME
- Poor counselling
- Apathy / disinterest
- Poor work up / referral

However more research is needed to properly understand the obstacles to donation. Within the BAME community there are various races, cultures, languages and religions (including Muslim, Hindu and Sikh). Each gives a different degree of importance to influence from parents and religious leaders.

AS has proposed that in order to overcome apathy, a priority system be introduced which favours those who i) have been a living donor or ii) have been on the organ donor register for at least three years prior. This system already runs in Israel. If nothing else, canvasing the idea will get people talking.

- Kings are doing a study called DONATE, working to increase understanding through better communication with the BAME community.
- In Birmingham, the QEHB is working with Kidney Research UK to train Pakistani Muslim peer educators who will be sent out to speak to ethnic groups
- The NWS Asian Intervention Project is examining perceptions in the community

Living donor rates have increased and there are now three altruistic donors from the BAME community. No single strategy is going to overcome the problem - more research is needed.