Welcome and introduction

Chair Chris Burns-Cox (CBC) welcomed guests to this, the charity’s fourth AGM, held at the DoubleTree by Hilton London West End Hotel.

Chair’s report

The Chair’s Annual Report was circulated. CBC explained that we are still some way from achieving our ambitious vision that there should be “no wait for a kidney transplant for lack of a kidney”. Indeed there would seem to be a slowing of the previous rapid increase in altruistic donor numbers. However an altruistic kidney donation is more likely now than ever before to trigger a chain, meaning that more people benefit from a single altruistic (or non-directed, non-specified, unrelated or non-related) donation.

Having commissioned a repeat of our YouGov poll, three years after the original one, we know that more of the public are aware that it’s legal to give a kidney to a stranger.

Thanks are due to Paul van den Bosch, who continues to respond to emails sent to the charity’s gmail address; to our PR Officer Jan Shorrock for updating Twitter and Facebook and for taking over the website, overseeing 48,890 visits during the year (up from 24,457 in 2013). Thanks also to Curious Road Design who are redesigning the website free of charge and JFA systems, through Jim Fatah, who is overseeing the re-build and continues to host.

We have welcomed David Lee, Economics Adviser with CH2M Hill, on to the Steering Committee, who is working on an incremental work plan for the charity. Thanks as ever to Viv Calderbank for producing wonderful quarterly newsletters: guests are asked to send her ideas for inclusion whenever possible. Thanks to Sanjiv Gohil for keeping the finances strictly under control; to all the various fundraisers and donors and to Chartered Accountant Chris Boustead for producing an annual financial statement at no cost to us. Give a Kidney is involved in research projects around the whole subject of altruistic donation, with David Hemmings as representative on these projects.

The Steering Committee met six times during 2014. While honoured to be Chair of Give a Kidney, CBC hopes to find a replacement for January 2016 who would bring some new ideas to the charity.

CBC asked that anyone willing to contribute to research carried out by Simon Baron-Cohen, a Professor of Psychology at Cambridge, with expertise in autism, empathy and altruism, should let Suzanna know.

Enquiries to our website

Paul van den Bosch responds to emails sent to giveakidney@gmail.com and explained that these generally fall into four categories:
1. Offers from abroad to sell a kidney
2. Individuals abroad wanting to set up a similar organisation – it’s often not easy to donate a kidney in other countries
3. Medical questions, for example ‘how much time will I need to take off work’
4. Enquiries from young people, often age 17-19, strongly motivated but facing apprehension from staff at a transplant unit (living donation is illegal under the age of 18).

This last prompted some discussion: should Give a Kidney ensure that young people are welcomed if they would like to donate a kidney? Lisa Burnapp (NHS BT) pointed out that it’s difficult to establish that it’s in the best interests of the patient to give a kidney at such a young age. Staff at transplant units do have the right to turn down offers, but if they do this, must direct individuals to another unit.

Sometimes interest has been generated through the schools programme, where students are encouraged to sign up to the organ donor register, at other times due to a family member being in need of an organ. Individuals differ in terms of maturity and suitability, so must be judged on a case by case basis.

In conclusion: Give a Kidney should support young people by providing full information on the process; should encourage health professionals to listen to young people and to respect their wishes, rather than seeing them as a problem; where possible, should provide a place where they can discuss their wishes (eg. Facebook conversations, email), so that they are having a conversation rather than just reading text.

Treasurer’s report

The Treasurer’s report was circulated, showing a balance on 1st Jan 2014 of £4,398.80 and on 31st December 2014 of £14,629.68.

Expenditure of £22,860 was made up of the following:

- Administration: £4,818
- Public relations: £8,885
- Travel expenses for SC members: £845
- Miscellaneous expenses including: YouGov survey (£2,340); AGM (£1,163); promotional t-shirts, badges etc (£1,199); newsletter printing (£325); PO Box (£303); JustGiving charges (£216)

Income of £33,101 came in from the following sources:

- JustGiving £4,845
- Charities Aid Foundation £4,800

We are very grateful to the following fundraisers for their generous support:

- Paul Dooley and Anne Dooley who raised £15,127
- Jasie Rae, Barclays, Sikh Temple Swindon who raised £3,006
- John Redpath who raised £2,828
- Little Britain Lodge which raised £2,491
- John Gould who donated £1,000
- Judith Becker whose articles prompted donations from IPC Media of £750
- Luc Delauzun who has raised £697 to date through the Ocean Floor Race which takes place in March 2015
- Stephen Lloyd for a donation of £500
- Rachel Kavalier who raised £408 in connection with her wedding
- Damien Rose who took part in the Edinburgh half marathon and raised £134.

**Confirmation of Trustees**

The Trustees were confirmed as follows: Chris Burns-Cox (Chair), Sanjiv Gohil (Hon Treasurer), Paul Gibbs, David Hemmings, Sara Stacey and Paul van den Bosch.

**Lisa Burnapp: Who gets your kidney?**

Living Donor Kidney Transplant 2020 is a strategy with the aim “to develop world class performance in living donor kidney transplantation”. There are three key objectives, one of which focuses on the contribution of altruistic donation and its potential to expand the pool of available kidneys in the National Living Donor Kidney Sharing Schemes. This is in recognition of the importance of this relatively new and growing activity. The aim is to increase living donor kidney transplantation overall from 18.5 / million of population to 26 / million in 2020. Although the number of altruistic donors (ADs) was 3% higher in 2014 than 2013, the big increases in numbers are slowing. It may be that we have reached those who are most willing or able to volunteer to donate and now need to consider different audiences. Altruistic donation has become less novel so media interest is more difficult to capture.

**Allocation**

Because there are more potential recipients than organs available for transplant, a UK-wide system has been developed to ensure allocation is equitable, transparent and as fair as possible. It is nationally agreed and reviewed regularly and is published by NHS BT on their website.

Patients are selected after assessment by their transplant centre and must give their consent to be listed on the National Transplant List. They are reviewed annually and their clinical and scientific data is updated on an on-going basis.

To allocate a kidney from a deceased donor, minimal information is required: blood group, HLA type, age and recipient waiting time. Patients are prioritised according to evidence-based computer algorithm, with five tiers (A-E).

Children under 18 are prioritized (A) and there is a points based system applied to C, D and E, with seven elements considered: waiting time (from ‘active’ listing); HLA match and age combined; donor-recipient age difference; location of patient, relative to donor; other HLA and blood group considerations (three elements).

The kidney and donor are registered with NHSBT and a national kidney matching run is performed. The kidney will be offered to a transplant centre for the patient with the highest point score. The transplant centre then confirms compatibility (HLA cross match) between donor and recipient and either accepts or passes on the kidney; if not accepted, the kidney will be offered to the next on the list.

Where living donors are involved, the process is different and can be planned in advance, but the principles are similar.

**Donor chains**

Any AD can choose to donate into a donor chain if he/she is willing to wait to be included in a matching run with the paired/pooled scheme (every 3 months). In a chain, an AD donates to a
recipient in the paired/pooled scheme and the incompatible donor for that recipient donates to someone on the national waiting list. This means that two transplants (short chain) are triggered from one altruistic donation. There have been 48 short chains since January 2012, leading to 96 transplants.

From April 2015, designated ‘sharing fortnights’ for surgery across all UK transplant centres will mean that entering a chain for an AD will be more attractive as delays will be reduced and dates of surgery more predictable within the schemes. Longer chains will also be created, with one donor triggering three transplants. The option of matching runs every two months from 2016 is also being looked into to see if this will be beneficial for patients waiting for a transplant and helpful in reducing waiting time for Ads who choose to create a chain.

**Hannah Maple: an update on research around altruistic donation**

The retrospective study that many of those assembled took part in (altruistic donors up to November 2012) is now in print.

A five year study with the title “Unspecified Living Kidney Donation in the UK: Barriers to Implementation and Delivery” will begin early this year thanks to a large grant from the National Institute for Health Research. The team aims to provide a comprehensive assessment of unspecified kidney donation in the UK, with three main questions:

1. Is there variation in transplant professionals’ practice and attitudes, which is preventing some unspecified donations?
2. Are psychosocial and physical outcomes after unspecified donation equivalent to those after specified donation?
3. What is the economic benefit from unspecified donation?

To assess transplant professionals’ practice, there will be focus groups from high and low volume centres, with interviews with 60 transplant professionals - Nephrologists, Surgeons, Co-ordinators, and Psychologists / psychiatrists, through a questionnaire study across the UK.

To assess outcomes in donors, again there will be focus groups of donors from high and low volume centres. A prospective donor study will involve four questionnaires at different time points: i) at presentation, ii) pre-operatively, iii) three months after donation and iv) 12 months after donation.

Those who do not donate (withdrawn / withdraw) will also be assessed, with questionnaires at three and 12 months, to assess the impact of not being able to donate or of withdrawing. Additionally there will be 45 interviews with donors across both groups.

The economic analysis will focus on whether unspecified kidney donation results in extra costs compared to specified donation. Also to discover what is the economic benefit of unspecified donation in both direct donation and altruistic donor chains.

**David Lee: YouGov survey results three years on**

Following the YouGov poll carried out in August 2011, Give a Kidney commissioned another survey which was carried out - online - between 8th and 11th August 2014. The figures have been weighted and are representative of all UK adults (aged 18+). The sample size was 2079 adults. Results were found as follows:
Potential to be a donor:
- The proportion of people who would consider donating to a family member has reduced from 74% to 67%
- The proportion of people who would consider donating to an unknown recipient has increased from 8% to 11%

There is little improvement in knowledge around kidney donation since 2011.
- More people know that non-directed kidney donation is legal (from 67% to 79%)
- Most people know that a person only needs one kidney to live (over 90%)
- Fewer than 40% know that no lifestyle changes are required after donation.
- Only 40% of people know that no lifestyle changes are required.
- 45% of people who would consider living kidney donation believe some lifestyle changes are required after donation.
- For people who are not sure whether they would like to donate, only 29% of them know that no lifestyle changes are required.

Helping people to understand the consequences of kidney donation might well lead them to decide to donate.

Awareness of Give a Kidney, the charity:
- Only 5% of people had heard of Give a Kidney.
- Of those who would consider non-directed kidney donation, only 9% of them had heard of Give a Kidney.

As an unknown charity, this makes it difficult for us to deliver our message to the public.

Potential to donate:
The size of the bar shows the number of survey participants in each group (Female/ Male). Within each stack bar, the percentage shows the proportion of participants who would or would not consider living kidney donation – adding up to 100%.
It could be viewed as the likelihood of a person in a specific group who would consider living kidney donation.
By age group (55+ / 45-54 / 35-44 / 25-34 / 18-24):
- People at 25-34 and 35-44 have the highest proportion of people who would consider non-directed kidney donation.
- People at 35-44 and 55+ have the highest number of people who would consider non-directed kidney donation.

By region:
- People in north and south regions have the largest number of people who would be likely to consider non-directed kidney donation.
- People in Scotland have the largest proportion of people who would consider non-directed kidney donation.

Social media use:
- 64% of people use Facebook monthly or more.
- 22% of people use Twitter monthly or more.

We should use Facebook to deliver our message as Facebook users have the highest number of people who would consider non-directed kidney donation. Interestingly Google+ users are the highest proportion of people who would consider non-direct kidney donation (22%).

13% of people who use Facebook would consider non-directed living kidney donation. Although not a particularly high percentage, Facebook has such a large user base that 13% means big numbers. However it does need to be actively managed and messages screened (see Jan Shorrock’s talk above) to ensure messaging is consistent and donor anonymity is not jeopardised.

The most important finding of all is that the best source of potential donors are those who are either on the organ donor register, bone marrow register or who donate blood regularly; these are all more likely to consider non-direct kidney donation. Of those who do not do these things, only 7% would consider non-directed kidney donation.
The highest number of people who would consider non-directed kidney donation is on the NHS Organ Donor Register. The Bone Marrow Register has the highest proportion of people who would consider non-directed kidney donation.

23% of blood donors, 20% of those on the organ donor register and 41% of people who are on a bone marrow register would consider non-directed kidney donation.

These organisation should work together to promote non-directed kidney donation. If people in these target groups knew more about it, the consequences, how it’s done and the value of it, they should be the most easily persuaded. We should tackle any misconceptions.

Jan has already been in touch with the Anthony Nolan Trust to see if there is a way of contacting those on their register, in particular if over 30 (in which case too old to register) or over 65 (can no longer donate bone marrow). Might they be willing to work with us to reach these potential donors? We are waiting to hear the result of internal discussions.

Blood donor centres are run by NHS BT and manned by staff who might not feel able to field questions on non-directed donation. However a major transformation is going on within the organisation and Lisa advises us to wait. Only NHS BT branded leaflets can be distributed here, but she is hopeful that information on altruistic donation can be included at a later date.

In the meantime, guests are encouraged to leave copies of our newsletters behind, wherever they feel able.

Jan Shorrock: a year in the media and lessons learned

Give a Kidney has generated some excellent press coverage over the year. Highlights include: a front page on the Sunday Telegraph, with full page feature inside; a six page Observer Magazine feature; a feature in the Independent; a double page spread in the Metro; a Sky News interview; a BBC Radio 5 Live (Breakfast show and hourly news slots); ITV News (Daybreak) and regional news programmes; German and Ukrainian TV interviews; a BBC Scotland Documentary; as well as many local press stories, women's magazines, community magazines etc.

In addition, some members have initiated contact with the press: Nicholas Crace on Jeremy Vine; Judith Becker in Women & Home and Bonmarche; Paul Dooley in Scottish News; Sue Gianstefani in Mail / Express / Take a Break / Women's Own etc.

In contrast Men's health magazines have proved harder to interest!

The website has seen visits increase by 105%, from 26,027 to 53,276 visits, with visitors increasing in number from 21,127 to 45,403.

Facebook 'likes' have increased from 166 in October 2013 to 818 in January 2015, and Twitter followers have increased from 235 to 469 in the same time period. There is an increasing amount of interaction with followers, with likes, shares and re-tweets, including a re-tweet from celebrity Peter Andre to his over three million followers (his brother died of kidney cancer).

We have lots of examples of people who decided to give a kidney as a direct consequence of reading a news story or hearing a radio interview with an altruistic donor. ADs are asked to let us know if that's the case, as it's great for a donor to hear they have been an inspiration.

We are grateful to all those who shared their stories with the media. Jan has a good relationship with NHS BT’s Press Office. It’s important the two work together so that messages are clear and
consistent. We are grateful for the information they share and in turn, we are able to put them in touch with donors and help with stories.

Do be aware that media attention can bring unwanted attention from trolls. If you come across negative messages like this, do feel free to step in to the conversation and politely correct them.

Messages do need to be monitored. For example a Facebook message saying “I’m donating my kidney to a stranger next Tuesday” puts the donor’s anonymity at risk. Others are inappropriate, for example: “I’d like to sell my kidney for $400,000, please call me.” For this reason posts are not shown until authorised.

Be aware too that there is such a thing as bad press where altruistic donation is concerned. A misleading or ‘bad news’ story could put potential donors off. We need to put out clear, informative, simple messages, so that increasingly it will become something that is not considered unusual.

Declining interest from the press is an issue. They are increasingly looking for new angles, in particular for donor and recipient relationship stories. Those who have met can be very helpful. What they would really like is for an altruistic donor to meet his or her recipient and fall in love!

Jan plans to continue to focus on local and regional press as they are always interested in local donors and stories. New personal stories that capture the imagination or speak to specific audiences are also helpful; reaching people like you (shared faiths, shared professions etc).

Significant numbers (500th AD, 50th chain etc), will always promote interest; new angles (paired and pooled, the added benefits of donation etc). Jan envisages a period of more intense promotion around a particular angle twice a year, probably in Spring and Autumn.

We will also look into other marketing approaches: we are revising our information leaflet which will be given out to potential donors; Lisa hopes to include information on NHS Blood Donor leaflets; we will work to improve relationships with other charities, who might share our work with their supporters, eg. Anthony Nolan; we will ask members to raise awareness through social media activity.

We will also work on a list of organisations whose members are more likely to be interested in donating a kidney, then ask to put a piece in their newsletter or buy an advertisement. U3A group, Quakers and Rotary have all been approached in the past, but have advised that they prefer a local person to act as advocate, rather than their central office sending out speakers.

Panel discussion

Guests were divided into groups to discuss various questions.

How to keep the momentum going?

- Give a Kidney leaflets to be distributed to all NHS transplant centres
- Find ways to inform GPs and other medical professionals, so that anyone interested in AD will be directed promptly to those who can smooth the path
- Add information on AD to existing NHS communications eg. on signing up to the ODR or giving blood
- Contact the armed forces
- Keep messaging consistent and clear
How to identify and reach likely donors?

- Identify potential celebrity supporters and ask for help with publicity (as Gary Lineker supported leukaemia charities after his son was diagnosed with the disease)
- Contact people on the blood donor database
- Think of groups which are excluded elsewhere eg. LGBT community excluded from donating blood
- Appoint a ‘Youth co-ordinator’ to deal with enquiries from young people appropriately

How to identify a specific and measurable project that we can then raise funds for?

- The main task of the charity is to raise awareness
- Start a living kidney donor register along the lines of Anthony Nolan’s
- We’re a small charity so seek advice: is there a think tank?
- Can we offer to train volunteers to talk about AD?
- online discussion forum or ‘members only’ area on our website to post ideas
- combine fundraising and awareness raising, for example with coffee mornings

How to create a reliable source of funding?

- Membership subscriptions
- Donations from the press in return for stories
- Approach pharmaceutical companies
- Benefit from BBC Radio 4 appeal - and other press appeals
- Local radio and TV stations
- Fundraisers: Great North Run, Marathons etc – approach sports clubs
- British Transplant Games in August

Should Give a Kidney play more of a political role?

- Lobbying is very expensive, with lots of groups competing for politicians’ attention
- First we would need to identify what we are asking the government to change
- NHS BT already operate in this area
- We can influence commissioners by being part of consultation groups, associations and other interested parties eg. Transplant 2013, BKPA, All-Party Parliamentary Kidney Group

Paul thanked guests for their contributions, which will be discussed at the next meeting of the charity’s Steering Committee.

Richard Pitman: Persuading others to jump the fence

Richard describes becoming an altruistic donor as ‘the best thing I ever did.’ He is delighted to help with publicity wherever possible. He was offered the opportunity to go on The One Show with his recipient, but his recipient pulled out: putting yourself in the public eye is not for everyone.

Richard feels that it’s very important for altruistic donors to talk about their experience, so that others realise ADs are not in any way incapacitated – or unusual. Richard loves talking about it, knowing that each occasion might just inspire another person to give a kidney as he has done. He is friends with Clare Balding who has a big Twitter following, so he’ll ask her to re-tweet on our behalf.
Richard talks to groups whenever possible. Recently he spoke, with David Hemmings and Jan Shorrock, at a ‘Lifesavers’ event in Oxford. This campaign was set up by a group of medical students and junior doctors to raise awareness with clinical practitioners and the general public about organ donation. Special interest groups like this are an ideal audience.

Chris reminded guests that there are other websites which are helpful, in particular livingkidneydonation.co.uk which is run by Di Franks and is full of personal stories from people interested in altruistic donation.