

## **Give a Kidney AGM & Conference Saturday 30<sup>th</sup> January 2016**

### **Welcome and introduction**

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

### **Chair's report**

CBC presented the Chair's report (available as a separate document [here](#)).

He welcomed Di Franks to the meeting. Di has supported over 140 people through living kidney donation, providing someone to talk to, since 2009. Her website is [livingkidneydonation.co.uk](http://livingkidneydonation.co.uk)

Sue Gianstefani asked guests to consider taking part in the British Transplant Games, taking place this year from Thurs 28<sup>th</sup> to Sunday 31<sup>st</sup> July in Liverpool.

Further details on how to register can be found here:

<http://www.britishtransplantgames.co.uk/> - however there will not be a separate team for altruistic donors this year. Anyone wishing to enter as a living donor should register under their hospital team, where they had their surgery.

Trustees were confirmed (CBC, Roger Corke, Paul Gibbs, Sanjiv Gohil, Sara Stacey, Paul van den Bosch and Robert Wiggins). CBC announced that he will step down as Chair at the next Trustees meeting, when Trustees will elect a new Chair. He intends to remain as a Trustee, as involved as ever with the charity.

### **Sanjiv Gohil: Treasurer's report**

The Treasurer's report was tabled (attached [here](#)).

SG thanked Graham Healey who has prepared the annual accounts for 2015 so promptly. These can be found on our website on the 'About us' tab.

SG pointed out that while we have spent just over £20,000, income was just under £13,500. We have been very fortunate to attract large donations every so often but we should not rely on these "windfalls" and need to look at how we can raise more regular, smaller donations through the website and text facilities. It should be simple and quick to donate through as many channels as possible, starting with an appeal to our members and supporters.

In no particular order, SG thanked donors Nicholas Evans, Jasie Rai, Barclays, Cherry Williams, Jackie Andrews, Geoff Roberts, JC Robinson Trust, Aviagen

Limited, Charles Ward, Thringstone Primary School and York Medical Society for generous sums given over the past year.

SG asked for attendees' views on whether we should spend on conferences and events. It was agreed that we should spend carefully and set a budget for this expenditure. We should also look for ways to partner with other organisations who might also be attending and able to speak for us. An expenses policy has been introduced to allow for reimbursement of volunteers' expenses, where appropriate.

### Lisa Burnapp: Living Donor Kidney Transplantation: Where we are now

In July 2014 the LDKT 2020 strategy set out: *"To match world class performance in living donor kidney transplantation"*

LDKT transplant rates for Europe and the USA in 2014 show that since 2011 the UK has moved from 5<sup>th</sup> to 3<sup>rd</sup> in the world ranking with 17.3 living donations pmp (per million population). The UK comes behind The Netherlands with the highest rate of living donation (31.8pmp) and Denmark (19.6pmp).

Objectives of the LDKT 2020 strategy are to: 1) increase LDKT activity, with state of the art donor care; 2) embed the principle of 'transplant first' (before dialysis) and improve equity of access to LDKT; 3) ensure the National Living Donor Kidney Sharing Schemes (NLDKSS) are clinically and cost effective.

The Strategy Implementation Group is chaired by Aisling Courtney, a nephrologist from Belfast in Northern Ireland, with support from NHSBT and representation from the wider transplant community on each of the four work streams: Commissioning, Access and Availability, Donor Safety and Recipients with Higher Immune Risk.

The activity targets within the strategy are ambitious, aiming for 26pmp by 2020, approximately 1700 living donor transplants per year. Currently, there are approximately 1100 transplants performed each year, which is below where we hoped to be this year. 2015/16 targets are 102 per month / 19.0 pmp (currently 16.5pmp). This has been met in months where there is an increase in transplant identified in the NLDKSS matching runs.

There is variation in activity across the UK and within England, which is being addressed through the strategy. There are many reasons for variations in activity but, in Northern Ireland, where there is enthusiasm and investment in living donation and a predominantly Caucasian population of willing and suitable donors, activity has increased dramatically in the last few years.

In comparison, England is more culturally and ethnically diverse and there are 19 transplant centres with multiple referring kidney units, which adds to the complexity of the programme.

The key priorities in delivering the strategy aim to address the shortfall. There is no new money available but ensuring that the programme is commissioned properly is important to sustain activity. The aim is to make the most of available living donors

through the National Living Donor Kidney Sharing Schemes. This year, a UK-wide survey of transplant and referring kidney units was undertaken to understand the barriers to LDKT. A public engagement initiative aims to attract and inform more potential donors.

Donor and recipient information has been revised and rebranded, as has the NHSBT website, with a new emphasis on how to go about donating. LB thanked Give a Kidney's PR Officer, Jan Shorrocks, for her input. There are also plans to display Information at blood donor sessions in future. A donor focus group was run in October to ensure donor engagement in delivering the strategy. A 10 year donor follow-up report will be published by NHSBT this year and UK guidelines for living donor kidney transplantation are being revised by the British Transplantation Society Standards Committee.

More donors are opting in to trigger a chain of transplants in the kidney sharing schemes (after first checking there is no higher priority on the waiting list): there are quarterly matching runs in January, July and October with dedicated weeks of surgery to facilitate as many transplants as possible within 8 weeks of the matching run. 76% of donations now proceed within a specific time frame.

#### Isobel Gordon: Eight years of altruistic donation: a single centre experience

The data includes all NDAD referrals assessed at Guy's and St Thomas' (GSTT) from 1st April 2007 to 31st March 2015

To clarify the definition, a non-directed altruistic (or unspecified) donor (NDAD) does not know, or has never met the recipient.

The Human Tissue Act in September 2006 was followed by the first NDAD operation in the UK in 2007. The UK now has the largest NDAD programme in the EU.

Of the 23 UK transplant centres, GSTT is one of the highest contributors with 35 during the period, beaten only by Portsmouth (42), Manchester (37) and Plymouth (36). Birmingham's ethnic population means that it is one of the highest recipient centres (36), but a low contributor (13), whereas GSTT is high on both (28 recipients, 35 donors).

The referral pattern for Guy's shows that most NDADs come from London, Kent, Sussex and Surrey.

The pathway to donation starts with self-referral from a potential donor. The centre responds with written information and a registration form, with or without telephone triage. This proceeds to an initial consultation with a Consultant or Specialist Nurse, including a preliminary health assessment if appropriate. Next are medical and mental health assessments, then surgical review and finally, HTA approval. The 18 week standard for donor assessment is difficult to meet when donors need additional assessments/specialist opinions and there are some delays in accessing mental health assessments.

The primary motivation of 29 proceeding donors was found to be as follows:

Blood donor/ODR	10%
Close to recipient/directed donor	21%
Life event-loss/bereavement	10%
Philosophy of life/faith	28%
Media story	21%
Another NDAD in the family	7%
Terminal illness	3%

The primary motivation in the 51 non-proceeding donors were as follows:

Blood donor/bone marrow/ODR	18%
Close to recipient/directed donor	8%
Life event/reparation	10%
Philosophy of life/faith	20%
Media story/Give a Kidney	14%
Another donor in the family	4%
Healthcare Professional	4%
Chronic illness	2%
Payment	2%

Of the 29 donors who proceeded:

- the average age was 50 (against the UK NDAD average of 55)
- the greatest number (13) was age 50-59
- the next greatest number (5) was age 40-49.

Of the 51 non-proceeding:

- the average age was 46
- the greatest number to withdraw (11) was in age groups 18-29, 40-49 and 60-69

More men than women came forward and of the 29 proceeding, all but one was white, so very similar to the UK figure of 98% white.

From 131 enquiries, 30 (23%) went on to donate. The greatest number (40%) dropped out very early in the process, after initial referral.

The average length of inpatient stay (date of donation to discharge) was 4.4 days.

In summary, Guy's is a leading contributor to the UK NDAD programme and reflects UK trends in donor characterisation, activity and outcomes. The centre gains as much as it contributes from the UK NDAD programme.

Donor triage throughout the assessment pathway is effective, although the duration of donor assessment falls short of the agreed standard. Relatively few donors have chosen to 'opt in' to an altruistic donor chain but this should increase in future.

**Emma Massey PhD, Assistant Professor Health Psychology, Nephrology & Transplantation: Psychosocial evaluation of unspecified donors in The Netherlands**

There are eight transplant centres in The Netherlands, which has a population of about 16.9 million.

Living donation is much higher than the UK - 31 per million population (pmp) against 17 pmp in the UK, however 9-10% of the living donor pool is unspecified which is comparable with the UK.

Deceased donation is about 16 pmp in the Netherlands, which is similar to the UK 21pmp.

There has been a steady increase in requests for information as well as actual donations since the start of the programme and the website re-design in 2014. Being so user-friendly, the website makes it easier for prospective donors to find the information they need and make contact by completing an online form. They can also send a question to a person from a specific profession.

Between 2000 and 2015, 128 unspecified donations proceeded in Rotterdam, resulting from 317 enquiries. 5% of applicants were declined on psychological grounds. 215 transplants resulted, as 60% of these were part of a chain.

Dutch guidelines for living kidney donor evaluation (June 2008) set out the following contraindications for directed donors: active psychosis or addiction, personality disorder and psychosocial instability.

For specified donors, the standard team required includes a nephrologist, a social worker, a nurse practitioner and a living donor / transplant coordinator. For unspecified donors, there is an additional psychiatrist (in four centres); a psychologist (in four centres); and an independent physician (in one centre).

The clinical interview seeks to determine if there is any history of psychiatric illness; perception of reality; motivation for donation; voluntariness of donation; realistic expectations of donation; understanding of the associated risks; social support; emotional resilience. One centre also asks about religious background, dealing with anonymity and dealing with disappointment.

Five of the centres ask for completion of validated questionnaires, seeking to assess psychological symptoms (4/5), personality (3/5), coping (2/5), depression (1/5) and quality of life (1/5).

In addition, for unspecified donors, one centre will not allow the donor to donate to a specific group and in one, the donor may not be under 25 years old.

There is little evidence to support the necessity for this 'extra' evaluation. For example, a study undertaken by Maple et al 2014 (n=190) found there to be no difference between unspecified donors and specified donors on various counts

including life satisfaction, well-being, stress, distress, depression, anxiety, quality of life, self-esteem, optimism, social support & social comparison.

In conclusion, unspecified kidney donation has been steadily increasing in the Netherlands since 2000. As in other countries, all the transplant centres conduct extra psychological evaluation of unspecified donors, but still little is known about the reasons behind the high rate of withdrawal at points from enquiry to donation. There is little evidence for the need to psychosocially screen unspecified donors differently to specified donors.

### **Stephen Potts (SP), Consultant Transplant Psychiatrist, Royal Infirmary of Edinburgh: Altruistic kidney donation - mental health assessment in the UK**

Altruistic organ donation, also called “non-directed”, “stranger” “anonymous” and “unspecified”, wasn’t permitted in the UK until the Human Tissue Act 2004 came into force (late 2006).

After a slow start (22 in the first three years), ALKD numbers appear to be levelling off at 100 - 150 / year and constitute 10-11% of all living kidney donation. This is many more than initially anticipated, more than other countries (except Holland) and represents a huge cultural change in a short space of time.

Previously, a donor would approach a transplant centre and have an initial assessment by a coordinator (including a health questionnaire, GP info and baseline bloods). They would then be referred to a psychiatrist, before any invasive investigation “to ensure fitness to donate” and “to ensure there is no relevant psychiatric or psychological illness.” Former HTA Guidance for transplant teams and Independent Assessors asked that the IA must “be satisfied that the donor has no evidence of current or past mental illness that affects their ability to donate altruistically with full, informed consent.”

Problems with this HTA Guidance include that a “psychiatric” assessment was specified, rather than psychological; only mental illness was referred to; no guidance was given on how to assess; the purpose was very general; and the guidance was not based on any provision within the law or regulations linked to it.

A Yes/No decision was expected from the psych report, with no room for “yes but...” As well as no standardised approach to assessment, there was no central collation of psych reports in those approved. (If there were no mental health contra-indications, the psych report would go to the IA (but not the HTA itself) before transplant was approved.) Nor was there a collation (central *or* local) of psych reports in those donors *not* approved, so we simply don’t know numbers, reasons for not approving them, or their outcomes.

Furthermore, if there were contra-indications, there was no standard follow up: should the GP be informed, or psych services, or would the donor be free to approach other centres, which might approve the transplant?

In 2012, the process was reviewed and the HTA issued revised guidance, with a new category: directed altruistic donation. This was mainly to reduce the risk of concealed reward in this new category, with an enhanced IA assessment, in which the IA was expected to “probe body language”\*. The donor now had to sign declarations, and the HTA requirement for anonymity was removed from altruistic and paired/pooled cases.

This means that the HTA no longer mandates a psych assessment by mental health professionals in altruistic cases - but *does* mandate a quasi-psych assessment by non-mental health professionals.

The relevant clinical bodies (NHS-BT and BTS) and well as the WHO and Council of Europe continue to recommend mental health assessment of all prospective altruistic donors, but there is still no clarity over the content, process, focus or range of outcomes of these assessments.

American work from Mary Dew and colleagues, published in 2007, recommended an initial screening followed by a two-stage evaluation by independent mental health clinicians, an interview with donor’s next of kin, and a two week “cooling off” period. This work also identified risk factors associated with poor outcomes for donors, including psych history, current psych symptoms, substance misuse, financial pressures, limited capacity, ambivalence, self-directed motives (inc relief from guilt), stressors, poor support and secondary gain.

Given the lack of clarity in the area, practice varied widely in the UK. To reduce this variation, a consensus workshop was arranged in March 2015, bringing together 60 mental health professionals from the UK and Ireland who worked in the field of transplantation. Draft guidance were discussed and debated, redrafted and revised. The resulting document has subsequently been adopted by the BTS, and appears largely unchanged, in the forthcoming 4th edition of national guidance for the assessment and management of living donors. Key features are as follows:

Q1. Which potential donors should be referred (for example: those under 30, over 70, those with a history of contact with mental health service etc? )

A1. It was agreed that every prospective donor should be referred.

Q2. Who should do the assessments?

A2. Any suitably qualified mental health clinician who is sufficiently familiar with transplant procedures, risk and outcomes. Centres with access to more than one type of clinician can direct referrals accordingly and some cases may require assessment by more than one professional.

Q3. At what stage of work up should the assessment happen?

A3. After initial screening and clinical assessment by the transplant team, but before any investigations which carry risk.

Q4. With what information?

A4. A clear description of the reason(s) for referral and details of any past episodes of treatment. This to be supplemented by the assessor's direct enquiry into past records, with potential donors' knowledge that this will happen.

Q5. Purpose of assessment?

A5. To confirm *capacity*; explore *motivation*; explore *resilience* and available *support*; explore *expectations*; identify *additional risks*; clarify routes to *follow-up*; to exclude from donation.

Q6. How should it be undertaken?

A6. It should be tailored to the referral question, clinical circumstances and the professional background of the assessor. A clinical interview is essential in all cases. Additional elements as appropriate to include repeat interviews, third party interviews, standardised questionnaires and structured assessments.

Q7. To whom should the report be sent?

A7. To the referring clinician in the transplant team; the GP; any relevant mental health services. Not always to the potential donor.

Q8. What should follow-up requirements be?

A8. Assessors should identify routes to mental health follow-up of those who may need it after donation, both short and long term. Also for would-be donors declined on mental health grounds: there should be direct liaison with relevant mental health services and GP.

Reports and data should be collated routinely, with an agreed core data set.

*\* HTA requires an enhanced IA assessment, with one e-IA per centre, having additional training, to include an ability to identify body language which should promote a probing interview. Very few IAs are mental health professionals and the main focus is not on motivation but uncovering reward, coercion or duress.*

## AFTERNOON SESSION

### UPDATE ON CURRENT RESEARCH

#### **Emma Massey PhD, Assistant Professor Health Psychology, Nephrology & Transplantation**

**Alive Project:** Anonymity in Live Kidney Donation: Patients' and Donors' Experiences, Attitudes and Preferences

Researchers asked 258 anonymous donors and 156 recipients in seven transplant centres in the Netherlands and four in Sweden various questions with the aim of determining:

1. What are the personal experiences of recipients and donors with regard to anonymity?
2. What are the donors' and recipients' attitudes towards anonymity?
  - a) Do attitudes differ between donors and recipients?
  - b) Do attitudes differ between countries?

They found that the experience of anonymity is generally positive, although not all knew about the anonymity policy. Satisfaction with their experience of anonymity before and after the operation was high, the desire to meet the other party was low and actual meetings very few.

There was however an imbalance between donor and recipient views on anonymity. Despite low personal desire to meet, there was openness for a meeting if the other party expresses their desire to meet. Donors agreed more with the recipients' right to remain anonymous, than recipients themselves. Recipients consider the donors' right to know the other party higher than their own right to know the other party.

Swedish participants were more reluctant about meetings prior to transplantation than Dutch participants.

Anonymity before and afterwards should be the norm, however in the case that both parties independently indicate a desire to meet the other party, this should be allowed after donation / transplantation.

The study suggests further research would be helpful, after access to more evidence on outcomes of meetings, with further evaluation of the risks and benefits.

Petrut Gogalniceanu (UCL Medical School), Alexis Clarke (Research Fellow / Clinical Psychologist, University of Plymouth) and Annie Mitchell (Clinical Director and Associate Professor, Doctorate in Clinical Psychology, University of Plymouth): BOUnD study: Barriers and Outcomes in Unspecified (altruistic) living kidney Donation in the UK

The BOUnD study is an ongoing national assessment, over five years, of the state of altruistic kidney donation in the UK.

There is currently a great deal of regional variation, with just three centres responsible for 45% of altruistic living kidney donation. There are drop-out rates of around 65% from first contact by a potential altruistic donor with a transplant centre. The study will assess attitudes of transplant professionals regarding unspecified donation, as well as attitudes of donors, both potential and those who go on to donate.

Initially two focus groups met, consisting of six to 11 participants, and researchers worked to identify themes. From these themes, in depth interviews are carried out and participants are asked to complete questionnaires.

Staff focus groups included 35 professionals with eight separate roles. Interviews will involve 60 professionals.

The donors' study has included a focus group of 10 potential donors, interviews with 45 potential donors and questionnaires completed by over 1,000 unspecified donors, unspecified non-donors and specified donor controls.

The study team is multi-disciplinary, including transplant surgeons, clinical psychologists, nephrologists, health economists and statisticians, nurse specialists and Give a Kidney representatives.

Findings will be reported to NHSBT and the British Transplant Society and will feed into national guidelines for unspecified kidney donation, creating a protocol for the management of those coming forward to donate.

### **Paul van den Bosch, Trustee and GP: Frequently asked questions**

Queries through the website number about two per day on average, with a surge when there is national publicity. PvdB responds on behalf of the charity, or forwards them on to colleagues, where appropriate.

Queries can be divided roughly into various categories:

1. Wanting to donate to a relative / friend / partner in need of a kidney: PvdB suggests they speak to the team involved in the care of the potential recipient.
2. Asking for more information: these are signposted to the charity website.
3. Queries from overseas, sometimes developing countries, USA, or elsewhere in Europe: PvdB can sometimes signpost them to relevant organisations in

their own countries, or explain that to donate in the UK you have to be a UK resident.

4. Queries regarding eligibility eg. previously had breast cancer or have had blood transfusions and wonder if that precludes them from donating a kidney: in most cases, PvdB suggests they contact their local transplant centre.
5. Asking what to do next? Again, they can be signposted to our website for contact details of their nearest transplant centre.
6. The young: PvdB explains that under 18's are not allowed to donate and that some surgeons have reservations about under 25s.
7. Good questions from young people: "I am 21 and the surgeon said I'm too young, but I know of someone who donated age 20." PvdB explains the reasons for reservations in the transplant community, suggests they talk to their families to get them on board and that they consider waiting a few years. If they are determined however, they can approach another transplant centre.
8. Other questions include: recipients searching for a donor; those trying to sell a kidney, or to use donation as a way to access the UK; previous donors wanting to contact the charity.
9. More unusually, one query came from a person suffering from brain cancer who wanted to know whether this medical history would preclude living kidney donation and / or donation after death.

These queries throw up others for the charity:

- Should we follow up these queries and encourage enquirers to take the next step?
- Should we review outcomes, to find out whether we could have been more helpful?
- Is it reasonable or wise to put people in touch with others in the same situation?

These will be discussed at future charity Steering Committee meetings.

### **Bob Wiggins: introduction to the Ambassador Programme**

Give a Kidney Ambassadors are people who are willing to engage in expanding public awareness of non-directed living kidney donation as representatives of Give a Kidney.

In BW's case, the inspiration is Terry, the recipient of an altruistic kidney. Today he uses the time freed from dialysis to deliver meals on wheels two days a week and play golf - his great passion - on Saturdays, as well as spending more meaningful time with his many close family members.

Although some altruistic donors may feel that having donated, that is the end of it, others find that there is still so much more that needs to be done for the benefit of those thousands of 'Terrys' that are still waiting for a kidney, of which many hundreds will never get one.

Founding members of Give a Kidney felt that way. So far Give a Kidney has pursued the vision "no waiting for a transplant for the want of a kidney" by influencing change, collaborating with other organisations (related charities, NHSBT, etc) and

engaging with politicians. Also by supporting donors during the pre- and post-operative periods, providing resources and information; by raising awareness through engagement with media, by instigating and attending events to increase public awareness and very importantly, by supporting Members own initiatives to increase awareness. By increasing the focus on enthusing, empowering and supporting Members own efforts, we could achieve much more.

The charity has achieved a great deal and is in a position of influence, recognition and potential, giving us the opportunity to build on this strong foundation.

The recent decline in organ donations, both living and deceased, combined with the decline in national media interest (unless it has a particular angle of interest or can be sensationalised or dramatised) means more action is needed.

We will need to identify the prospective Ambassadors and to develop and produce a relevant package of support in a combination of print and online formats. Four areas of support have been identified: training, materials and resources, contact and mentoring.

We hope to provide information and trends relevant to non-directed kidney donation; inform about opportunities to engage with both local and national media and organisations; build confidence and skills for dealing with local and national media, organisations and groups; increase awareness of current issues around organ donation and the position of Give a Kidney to enable Ambassadors to be comfortable engaging in discussion on these topics

We need to develop a package of useful materials and resources in the form of generic, but adaptable, templates, examples and drafts for letters, articles, presentations, etc; current information and trends in non-directed kidney donation and organ donation in general ; possibly an Ambassadors' forum on the website to allow Ambassadors to share experiences.

We want to be able to provide useful contacts to Members for local media, organisations and groups and to offer Ambassador involvement in opportunities at a national level. We recognise that some Ambassadors would like one-to-one support and we envisage offering a mentoring service to provide Ambassadors with a point of contact for ongoing support, but also ensuring that established Ambassadors can help new Ambassadors as well as other Members interested in spreading the word.

We would welcome feedback on Members' own experiences, both good and bad; on ways they feel an Ambassador programme might be helpful and of course whether or not they might be interested in becoming a Give a Kidney Ambassador.

Over the coming months, we will be seeking expressions of interest from Members in becoming an Ambassador (whether donors, recipients or family members), developing the package of materials and resources, setting up training modules and holding a launch event in York on 25<sup>th</sup> June. Then we will roll out the programme.

## **Discussion topics:**

### **Jan Shorrocks (JS): the charity's 5<sup>th</sup> birthday celebrations**

JS explained that the charity will celebrate its 5<sup>th</sup> birthday in 2016. If we are to organise an event to mark the occasion, would members attend? What sort of budget should be allocated for such an event? How should it be funded: would guests be willing to buy a ticket? It was agreed that any financial contribution should be voluntary and that ideally the event would be sponsored. If anyone knows of any potential sponsor, they should let JS or Suzanna know, by emailing [giveakidneyoffice@gmail.com](mailto:giveakidneyoffice@gmail.com)

JS further explained that we expect the 500<sup>th</sup> altruistic donor to donate sometime in the Spring this year. She has considered tying publicity for this with our 5<sup>th</sup> birthday celebrations, however a public facing campaign around living donation is planned by NHS BT so it makes sense to celebrate the two separately and maximise publicity that way. NHS BT are going to set up a 'register of interest' so that people can approach their local hospital this way.

### **Chris Burns-Cox (CBC): raising awareness outside the UK**

CBC explained that we start by helping our family and those close to us, then our friends and acquaintances, where we can. CBC also considers it our duty to help those further afield, so long as it's not to the detriment of people in the UK. 'How to do good, better' is something we need to constantly look at.

Bob Wiggins is confident that by engaging outside the UK, we are punching above our weight and so also raising our profile and standing within the UK. The more countries that embrace altruistic kidney donation, the more likely we are to find numbers increasing here. We have already shared information with groups in The Netherlands, New Zealand and the USA and should continue to do so, where funds allow.