

## **NBTA MEETING: 4<sup>th</sup> OCTOBER 2016**

### **OFFER OF SUPPORT TO INCREASE THE NUMBER OF LIVING DONORS FROM THE BLACK AND ASIAN COMMUNITIES**

#### **1. CONTEXT**

The risk of end stage kidney disease (ESKD) in black and Asian and other minority ethnic (BAME) communities is more than three times higher than in the Caucasian population and the number of people waiting for a kidney from BAME populations is disproportionately high, currently comprising 30% of the overall kidney transplant list. In comparison with 882 days for white patients, median waiting time to transplant for adult black recipients is 1134 days and 1070 days for Asian recipients.

In London, 72% (n=813) of patients on the kidney transplant list are from BAME communities with 47% (n=381) Black, 44% (n=355) Asian and 9% (n=77) other ME groups. 28% of eligible deceased donors in London are from BAME communities with a range of 11-30% across transplant centres. Outside London, the main transplant centres with a significant number of BAME patients waiting for kidney transplant are: Queen Elizabeth Hospital, Birmingham 51%(n=205), Leicester Royal Infirmary 42% (n=71). Coventry University Hospital 39% (n= 32).

Overall, there is a lower conversion rate of potential living donors to actual donors from BAME communities in comparison with white donors due to predisposing factors such as diabetes mellitus and hypertension. This data is held by individual transplant centres but, experience suggests that only one in every three or four donors from BAME communities may be suitable to proceed to donation following assessment.

Latest statistics confirm that, in comparison with white communities, fewer people from BAME backgrounds:

- Give consent for deceased donation (33% BAME versus 66% white)
- Are aware of the Organ Donor Register (57% BAME versus 74% white)
- Agree that its important to share their decision about organ donation (38% BAME versus 59% white)
- Have had the conversation with family (27% BAME versus 48% white)
- Are aware of the organ donation decision of family members (77% BAME versus 83% white)

In living donor kidney transplantation (LDKT), the number of Black and Asian patients accessing LDKT is substantially lower compared with white patients with only 14% of BAME recipients transplanted directly from a family member or friend in comparison with 86% of white recipients. A number of barriers have been identified in the literature:

- Recipients' reluctance to initiate the conversation about LDKT.
- A lack of skills on how to identify and approach potential donors
- Concerns for the donor e.g. process being too difficult, financial cost, guilt, effect on other family members.
- Lack of knowledge about the donor process, surgical outcome, risks and impact on future health

- Insufficient culturally sensitive resources.
- Access to clinic/hospital- based education only

BAME donors are significantly under represented in non-directed altruistic kidney donation and engagement from these communities is low. 99% of non-directed donors are Caucasian but 24% of recipients of these donated kidneys are from BAME communities.

### **1.1. Work in Progress: Pilot Project Acceptance, Choice & Empowerment (ACE) in Living Donor Kidney Transplantation (LDKT)**

As part of delivering the Living Donor Kidney Transplantation (LDKT) 2020 Strategy, NHSBT is currently funding and working in collaboration with Kidney Research UK (KRUK) on a 1 year pilot project – ‘*Acceptance, Choice & Empowerment (ACE) in Living Donor Kidney Transplantation (LDKT)*’ from April 2016 to March 2017. This is the first UK pilot, specifically focused on increasing uptake of LDKT for Black and Asian patients with End Stage Kidney Disease (ESKD) and their families. Two pilot sites are enrolled- West Midlands (Queen Elizabeth Hospital, Birmingham- Asian patients) and South London (Guy’s & St. Thomas’ Foundation Trust, London- African and Caribbean patients).

Evidence suggests that BAME communities are more likely to donate to loved ones within their own communities than to engage with ‘general population’ donation appeals. The project aims to engage with BAME communities using a unique home-based education intervention with Peer Educator volunteers. It combines proven models from the Netherlands (NL), USA and the UK that have been effective in overcoming barriers within BAME family and friend networks to increase uptake of LDKT. ACE LDKT has the potential to offer an innovative, cost-effective, culturally sensitive solution to increasing LDKT in BAME communities.

The measurable outcomes for this project have been chosen so that they are realistic for the short duration of the pilot. As there is little data currently available, the aim is to provide benchmarks for future projects:

- 1) Number of expressions of interest from enrolled patients and their families about living kidney donation
- 2) Number of potential recipients taking up attendance at patient education sessions/events including prospective patients and reengage with ‘lapsed’ individuals/poor attendees
- 3) Number of home visits- uptake and attendance

The pilot project will also deliver:

- A toolkit/template covering governance processes, recruitment and training to inform future projects and roll out to other centres
- A qualitative assessment of the experience and reflections of participants (Individuals, families and friends, Multi-disciplinary team, Peer Educator Volunteers) based on focus groups and questionnaire surveys.

## **2. PROPOSAL**

NHSBT is making £90,000 available for an 18 month period from 1<sup>st</sup> November 2016 to increase the number of people from BAME communities who have an opportunity to be transplanted from a living donor. NBTA will agree which projects to support with the aim of delivering 25 people from the black and asian community who enter the assessment programme for living donation.

### 3. KEY PERFORMANCE INDICATORS (MEASURABLE OUTCOMES)

There is little existing data in this area to benchmark performance targets and therefore the following are recognised as stretch targets.

Within an 18 month project, proposed targets to be achieved are the numbers of donors from BAME communities:

- Seeking information/expressing an interest: 40
- Assessed for donation – **key measurable: 25**
- Suitable to continue to donation: 10

### 4. GOVERNANCE

NBTA to take responsibility for:

- Collectively identifying and agreeing the projects, assessing value for money and likely deliverability and the suitability of outcomes/key performance indicators against which they will be judged. A transparent decision-making process should ensure the confidence of all wishing to propose projects.
- Presenting the projects to NHSBT for sign off
- Performance managing the projects to deliver the agreed outcomes whilst supporting project leads to deliver
- Reporting progress quarterly to NHSBT
- Ensuring good financial governance is exercised through the body chosen to hold the funding on behalf of NHSBT

#### Sources:

1. Latest statistics and NHSBT Activity Reports, 2015/16  
<http://www.odt.nhs.uk/uk-transplant-registry/annual-activity-report/>
2. ACE LDKT Pilot Project April 2016 to March 2017, NHSBT/KRUK (in progress- full documentation awaiting publication)