

# Concern as the number of living-donor transplants in the UK continues to fall

By Kirit Modi, NKF Life Vice President

**N**KF is taking the lead in expressing grave concerns at the drop in the number of living-donor kidney transplants carried out in the UK over the past few years.

Statistics provided by NHSBT (NHS Blood and Transplant) reveal a substantial drop in the number of living-donor organ transplants (the majority of which are kidneys) carried out year on year. In the year 2013-14, 1147 living-donor transplants were carried out. By 2015-16 this number was reduced by 72 to 1075 – a 6% drop over two years. Statistics released by NHSBT in April (which may adjust slightly over the next month or so) for the year 2016-17 reveal a further reduction in the number of living-donor transplants carried out over the past twelve months. 1036 living-donor transplants were carried out in the UK in this period of time. This represents a drop of 3.5% on 2015-16 statistics and a drop of nearly 10% on 2013-14 statistics.

This trend runs contrary to the targets outlined in a National Strategy committing to increase the number of living-donor transplants year on year, published and signed up to by all four UK governments and NHSBT.

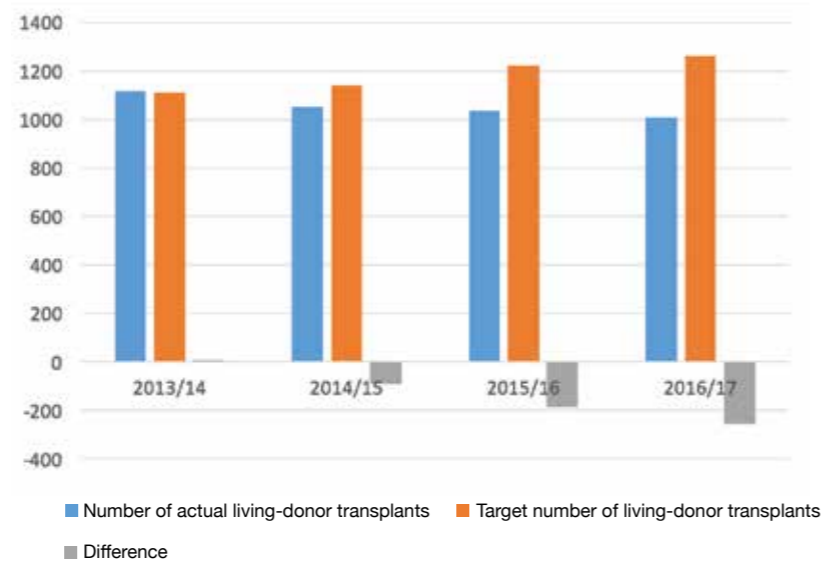
This bar chart shows the increasing gap between the numbers of living-donor transplants compared to the targets set. If this trend continues the target of 1728 living-donor transplants set for the year 2019/2020 will not be achieved.

These concerns were shared with the All Party Parliamentary Kidney Group (APPKG) at a meeting on 7th December 2016. The APPKG wrote to NHSBT, NHS England (NHSE) and the Chair of the Transplant 2020 Strategy Oversight Group to seek their views. In addition, NKF met with representatives from NHSBT, NHSE and the Chair of the Renal Services Clinical Reference Group to discuss the matter.

## What are the reasons for the drop in numbers?

### Possible causes are:

- **There is unexplained variation in the number of living-donor transplants undertaken by transplant centres.** A measure of how many transplants each of the 23 transplant centres in the UK carries out is based on transplants carried out per million local population (pmp). Provisional figures for 2015-16 presented at the Renal Transplant Services meeting in February 2017 reveal that these range from around 8 pmp to around 36 pmp. These figures also indicate that provisionally 15 of the 23 UK transplant centres are below the national average of 15.7 transplants pmp. While there are valid reasons for some variation, the extent of the variation remains unexplained.
- **Some hospitals do not employ sufficient Living Transplant Co-ordinators:** The nurses who support potential living donors and recipients through the process of living organ donation and transplantation are called Living Transplant Coordinators (LTC). They are employed by transplant centre hospitals as well as hospitals which send their patients to transplant centres for surgery. Evidence is emerging that some hospitals do not employ sufficient LTCs to encourage and then cope with demand for living kidney donation. This clearly affects the number of living-donor kidney transplants.



- **The support provided by LTCs to source potential living donors from family members and friends may not be appropriate.** It is very difficult for patients waiting for a kidney transplant to discuss the option of a living donor with close family and friends. Support is provided by the local LTC but the type of support varies. There is some evidence that offering this support in the home of the patient, particularly for patients from Black, Asian and Minority Ethnic (BAME) backgrounds may be more effective than in a group or hospital based setting.
- **Some kidney patients may prefer to receive a kidney donated after death rather than from a living donation.** There is some anecdotal evidence supporting this theory. The average waiting time for a kidney transplant donated by someone after death is now 2.5 years (3 years for BAME patients). Unfortunately, there is no national guidance for patients and donors about the advantages and disadvantages of one system of donation over the other.
- **Who champions living donation in hospitals?** For donation after death, hospitals have to establish a local Organ Donation Committee which is funded by NHSBT. However, other than the existence of a LTC there is no comparable arrangement supporting the system of living donation in most hospitals.

## There may, of course be other reasons for the drop in living-donor kidney transplants and these need to be identified.

### What is NKF doing about this?

The APPKG will hold a Living-donor Kidney Transplant Summit this year – date to be advised - within the Parliamentary Estate at Westminster. The Summit will include input from key individuals with expertise in living-donor kidney transplantation in the UK. It will investigate the reasons for the drop in numbers, consider what we should do about them and highlight good practice. Following the Summit, the APPKG will publish a Living-donor Transplant Manifesto which will set out clear recommendations for improving living-donor transplantation in England.

### How can Kidney Patient Associations and patients help?

Kidney Patient Associations (KPAs) and individual patients have an important contribution to make at a local level. If you are a patient or belong to a KPA affiliated to your hospital please make contact with your hospital's LTC and arrange a meeting with her/him. The issues raised above would provide a good basis for discussion at the meeting. The LTC should be able to provide details of the number of living kidney donations and transplants that have taken place at their hospital over the last couple of years. NB - NHSBT statistics are measured April to end March. From this meeting local issues may emerge and can be pursued further by the KPA.

### Next stages

A copy of the Manifesto for Living-donor Transplantation will be emailed to every KPA and will also be available via the NKF web-site. It would be immensely helpful if details of any local discussions about living-donor kidney transplants could be sent to NKF at [NKF@kidney.org.uk](mailto:NKF@kidney.org.uk) Thank you for your support in this initiative.

