

## UK LIVING KIDNEY DONATION NETWORK

### TERMS OF REFERENCE

DECEMBER 2024

#### 1. BACKGROUND

The UK Living Kidney Donation (LKD) Network was established in October 2017 as one of the initiatives from the *Living Donor Kidney Transplantation 2020 (LDKT 2020) Strategy*<sup>1</sup>. NHS Blood and Transplant, endorsed by the British Transplantation Society and the Renal Association (now UK Kidney Association), set it up to improve communication and enhance clinical leadership for living donor kidney transplantation (LDKT) across the UK in both transplant and non-transplant centres.

This multi-disciplinary network is Chaired by two clinical Co-Chairs and extends across all four nations of the UK. **It consists of Lead Nephrologists, Transplant Surgeons, Living Donor Coordinators, advanced kidney care colleagues, histopathology and immunogenetics leads and any other members of the multi-disciplinary workforce working in transplant and non-transplant centres interested in the development of LDKT (see section 4).**

#### 2. WHY DO WE NEED A UK LKD NETWORK?

To facilitate multi-professional education and engagement in LDKT by improving communication, sharing best practice and strengthening clinical leadership across the UK. The aim of the Network is to ensure that best practice is promulgated effectively in both transplant and non-transplant centres so that every recipient who is suitable for a transplant is offered the opportunity to consider the range of options available for LDKT (i.e., direct living donation, the UK Living Kidney Sharing Scheme, innovative antibody removal techniques) to avoid /minimise time on dialysis and promote best recipient and transplant outcomes.

#### WHAT DOES IT NEED TO ACCOMPLISH?

- a. To identify and address unwarranted variation in access to and availability of LDKT in the UK, regardless of geographical location, socio-economic circumstances, local ethnic and/or cultural diversity.
- b. To facilitate consistent best practice in living donor kidney transplantation in all transplant and non-transplant centres across the UK

#### 3. HOW WILL IT BE APPROACHED AND WHO WILL BE INVOLVED?

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<sup>1</sup> Living Donor Kidney Transplantation Strategy 2020 <https://www.odt.nhs.uk/odt-structures-and-standards/key-strategies/archived-strategies/living-donor-transplantation-strategy-2020/>

- a. **NHS Blood and Transplant (NHSBT)** will
- Provide leadership support to the LKD Network and its Co-Chairs via the Associate Medical Director (AMD) for Living Donation and Transplantation (LDT) and the Lead Nurse for Living Donation
  - Maintain and manage the network database and ensure appropriate governance/GDPR is applied to all communications to and from the network in consultation with the AMD-LDT and Lead Nurse
  - Provide secretariat support for the LKD Network Chairs and LKD Network (i.e., convening and minuting meetings, administration support for network events, uploading and updating digital resources)
  - Provide a dedicated website area on the [www.odt.nhs.uk](http://www.odt.nhs.uk) clinical website to support network activities.
  - Engage with other agencies (e.g., commissioners, industry partners) to secure funding for network activities such as an annual UK-wide meeting/regional events/Recipient and Living Donor Coordinator induction programme.
- b. **Professional Societies (British Transplantation Society (BTS) and UK Kidney Association (UKKA))** will
- Endorse the structure and approach of the network
  - Provide representation and support within the network
  - Engage members in network activities
- c. **Co-Chairs and Leadership**
- The network will be Co-Chaired by two clinical leads, incorporating representation as follows:
    - **Essential** - nephrology, non-transplant centre, UKKA nomination (one Co-Chair)
    - **Desirable** - multi-disciplinary team (MDT)
  - The Co-Chairs will be supported by the AMD-LDT, Lead Nurse and secretariat functions within NHSBT (as above).
  - Tenure will be for 3 years, renewable for one further term if nominated. Previous 2-term Co-Chairs can stand again after at least one term has elapsed.
- d. Change of Chairs will take place at the Spring UK LKD Annual Network meeting in the appropriate year (next due 2025, 2028). Nominations will be sought from the network membership and from the UKKA prior to commencement of office. New appointments will be announced at the annual Network meeting, with a formal handover from present to future Chairs at the meeting. Immediate past Chairs can support incoming Chairs if required to transition into the role.
- e. **Network membership**
- The 'core' network comprises clinical leads/champions for nephrology, living donor coordination and transplant surgery (transplant centres only), each self-nominated and endorsed by their individual transplant and non-transplant centres. All centres in the four nations of the UK are represented. Representation from advanced kidney care (AKC)/kidney care planning is also included in the network.
  - The wider network membership consists of any other members of the multi-disciplinary workforce working in transplant and non-transplant centres in a variety of clinical settings who are interested/involved in the development of LDKT.

#### **f. Activities**

- The UK- wide network will aim to meet face to face/virtually at least annually, funding dependent
- Ad hoc or regional events will be encouraged, funding dependent
- A Recipient Coordinator (RC)/Living Donor Coordinator (LDC) induction programme supported by NHSBT and BTS will run at least annually, dependent upon demand and available funding
- A regular newsletter will be distributed to the Network and uploaded to the dedicated area on the [www.odt.nhs.uk](http://www.odt.nhs.uk) website

#### **4. HOW WILL SUCCESS BE MEASURED?**

The success of the LKD network could be measured by its contribution to:

- Increased uptake of LDKT overall
- Increased uptake in LDKT in under-represented groups
- Increased rates of pre-emptive LDKT; overall and by centre
- Reduced unwarranted variation in uptake and proportion of LDKT between transplant centres and non-transplant centres across all metrics (as above)

#### **5. WHAT RESOURCES WILL BE REQUIRED?**

- Funding-** up to 10k/year to host a face-to-face UK wide network meeting in a suitable external venue and support an annual NHSBT/BTS recipient and living donor induction course in a NHSBT venue (funding historically provided by NHSBT)
- People-** AMD-LDT and secretariat support (provided by NHSBT); Co-Chairs released by individual Trusts; meeting attendees – time and travel supported by own Trusts
- Digital-** support from NHSBT digital team to upload/update resources; maintain dedicated website area