

## UK LIVING DONOR LIVER TRANSPLANTATION NETWORK

### TERMS OF REFERENCE

JANUARY 2024

#### 1. BACKGROUND

The UK Living Donor Liver Transplantation (LDLT) Network was established in January 2024 to support the expansion of LDLT across the UK. This is in line with the ambitions set out in the UK *Organ Donation and Transplantation 2030: Making a Difference Strategy*<sup>1</sup>, recommendations from the Organ Utilisation Group<sup>2</sup> and as one of the key outputs of the LDLT Project, which was established in April 2022. The aim of the project is to establish an adult-to-adult LDLT programme and provide additional support to the existing paediatric programme so that adults and children waiting for a transplant, across the UK, have access to the option of LDLT.

NHS Blood and Transplant (NHSBT), endorsed by the British Transplantation Society and the British Liver Transplant Group (BLTG) within the British Association for the Study of the Liver (BASL) set it up to improve communication and enhance clinical leadership for LDLT across the UK in both transplant and non-transplant (referring) centres. The LDLT Network is based upon the success of the UK Living Kidney Donation (LKD) Network, which was established in October 2017 to support living donor kidney transplantation UK-wide.

The first Co-Chairs of the LDLT Network, Dr. Steven Masson, Consultant hepatologist and Mr. Joerg-Matthias Pollock, supported by the Associate Medical Director for Living Donation and Transplantation (AMD-LDT) within the NHSBT Organ and Tissue Donation and Transplantation (OTDT) Clinical Team, have been appointed from within the LDLT Project to provide representation and clinical leadership for the network.

This multi-disciplinary network extends across all 4 nations of the UK and consists of Lead Hepatologists, Transplant Surgeons, Specialist Nurses and colleagues across the multi-disciplinary workforce, working in transplant and non-transplant/referring centres, who are involved or who have an interest in the development of LDLT.

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

To facilitate multi-professional education and engagement in LDLT 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 communicated 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

<sup>1</sup> Organ Donation and Transplantation Strategy 2030: Meeting the Need <https://www.odt.nhs.uk/odt-structures-and-standards/key-strategies/meeting-the-need-2030/>

<sup>2</sup> Honouring the Gift of Donation: Utilising Organs for Transplant – summary report of the Organ Utilisation Group, February 2023 <https://www.gov.uk/government/publications/honouring-the-gift-of-donation-utilising-organs-for-transplant/honouring-the-gift-of-donation-utilising-organs-for-transplant-summary-report-of-the-organ-utilisation-group>

of options available, including LDLT, to promote best recipient and transplant outcomes for all patients who are waiting.

### WHAT DOES IT NEED TO ACCOMPLISH?

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

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

- a. **NHS Blood and Transplant (NHSBT)** will
  - Provide leadership support to the LDLT Network and its Co-Chairs via the AMD-LDT
  - 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. Provide secretariat support for the Network Chairs and LDLT 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 British Liver Transplant Group (BLTG) within British Association for the Study of the Liver (BASL)** 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** – hepatology and transplant surgery
    - **Desirable** - multi-disciplinary team (MDT)
  - The Co-Chairs will be supported by the AMD-LDT and secretariat functions within NHSBT (as above).
  - Tenure will be for 3 years, renewable for 1 further term if nominated. Previous 2-term Co-Chairs can stand again after at least one term has elapsed.
  - Change of Chairs will take place at the Spring UK LDLT Annual Network meeting in the appropriate year (next due 2025). Nominations will be sought from the network membership and from the UKKA at the annual meeting in the year prior to commencement of office. New appointments will be made by early summer (June/July) so that a shadow role for incoming Chairs can be facilitated from September.
- d. **Network membership**
  - The 'core' network comprises clinical leads/champions for hepatology, living donor coordination and transplant surgery, each self-nominated and endorsed by their individual

transplant and/or non-transplant/referring centres. The aim is to achieve representation from all centres.

- The wider network membership consists of any other members of the multi-disciplinary workforce working in transplant and non-transplant/referring centres in a variety of clinical settings who are interested/involved in the development of LDLT.

#### e. **Activities**

- The UK- wide network will aim to meet face to face/virtually at least annually, funding dependent
- An 'all organ' 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 dedicated area on the [www.odt.nhs.uk](http://www.odt.nhs.uk) website will be developed to upload resources to support the Network

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

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

- Increased uptake of LDLT overall
- Increased uptake in LDLT in under-represented groups
- Improved equity of access to LDLT for suitable adult recipients
- Reduced unwarranted variation in uptake and proportion of LDLT between transplant centres and non-transplant/referring centres across all metrics (as above)

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

- a. **Funding-** up to 6k/year to host a face-to-face UK wide network meeting in a suitable external venue and contribute to an annual NHSBT/BTS recipient and living donor induction course in a NHSBT venue (funding historically provided by NHSBT)
- b. **People-** AMD-LDT and secretariat support (provided by NHSBT); Co-Chairs released by individual Trusts; meeting attendees – time and travel supported by own Trusts
- c. **Digital-** support from NHSBT digital team to upload/update resources; maintain dedicated website area