



The Voice of Transplantation in the UK

20th November 2017

Dear Colleagues,

UK LIVING KIDNEY DONATION NETWORK

Welcome to the UK Living Kidney Donation Network. This network has been set up by NHS Blood and Transplant, the British Transplantation Society and the Renal Association to improve communication and enhance clinical leadership for living donor kidney transplantation (LDKT) across the UK. Many thanks to those who have recently put themselves forward as Clinical leads for LDKT. All referral and transplant centres are now represented. The network will consist of Nephrologists, Transplant Surgeons, Living Donor Coordinators, Immunologists and any others who are interested are welcome to opt onto the mailing list.

The network will send out quarterly emails covering the following

- Tackling frequent problems in LDKT workup **How to...**
- Update on key LKDT publications **opinions from the experts**
- Upcoming events

Members will be surveyed later this year to see what topics they would like to see covered.

DATES FOR THE DIARY

Living Donor Forum 2017: Donor Risk: Caring Concern or Pompous Paternalism? How difficult is it for Living Donors to donate, November 24th 2017, 10:00 - 16.30, Mary Ward House, 5-7 Tavistock Place, London, WC1H 9SN

<https://bts.org.uk/wp-content/uploads/2017/11/Living-Donor-Forum-Programme-v6-2.pdf>

BTS Annual Congress 2018, March 14-16th, Brighton

<https://bts.org.uk/events-meetings/annual-congress-2018-2/>

UK Kidney Week, June 19th - 21st, Harrogate

<http://www.ukkw.org.uk/>

We are hoping to host networking meetings at BTS Congress and during UK Kidney Week.

LDKT resources for clinicians

The first Annual Report for Living Kidney donation was published by NHSBT in October 2017 and presents key figures about living donor kidney transplantation in the UK, covering 1 April 2002 to 31 March 2017.

https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/1312/annual_report_on_living_donor_kidney_transplantation_2016.pdf

Additional useful resources for UK Living Donor Kidney Transplantation Network can be found in **Appendix 1** (please see below).

Katie and I look forward to meeting you at the events over the next few months and to sharing ideas to take the network forward.

Kind regards



Dr Caroline Wroe
Chair of the UK Living Kidney Donation Network
Consultant Nephrologist
South Tees NHS Foundation Trust



Dr Katie Vinen
RA Lead for Living Kidney Donation
Consultant Nephrologist,
Kings College Hospital

Appendix 1 Useful Resources for UK Living Donor Kidney Transplantation Network

Resource	Weblink
Commissioning	
Commissioning Policy: Reimbursement of Expenses for Living Donors (NHS England), 2017	https://www.england.nhs.uk/publication/commissioning-policy-reimbursement-of-expenses-for-living-donors/
NHSBT Resources and Activity Reports	
Living donation and transplantation: guidance and resources	https://www.odt.nhs.uk/living-donation/
Strategy for Living Donor Kidney Transplantation 2020 (LDKT 2020)	https://www.odt.nhs.uk/odt-structures-and-standards/key-strategies/living-donor-transplantation-strategy-2020/
Annual Activity Report 2016/17 and slide sets Organ Donation and Transplantation Data for BAME groups (Supplementary report)	https://www.odt.nhs.uk/statistics-and-reports/annual-activity-report/
Annual Report on Living Donor Kidney Transplantation 2016/17	https://nhsbtbe.blob.core.windows.net/umbraco-assets-corp/5706/annual-report-on-living-donor-kidney-transplantation-2016_17.pdf
Donor-Recipient Information/Awareness Raising	
Donor and recipient information about living organ donation: interactive pdfs; 'Let's talk about...' Films; Interest Register (release date TBC); promotional materials (banners, flyers, printed leaflets)	<p>https://www.organdonation.nhs.uk/about-donation/living-donation/</p> <p>Printed and promotional materials are available to order online free of charge through https://www.nhsbtleaflets.co.uk</p> <p>Living donation banner stands can be ordered by emailing: leaflets@nhsbt.nhs.uk</p>
Organ Donation Scotland	https://www.organdonationscotland.org/tell-me-about-living-donation
Gift of Life (hard copy booklet)	Industry sponsored. Revised version due for publication in December 2017 available from Astellas or Sandoz representatives.
Give a Kidney Charity	http://www.giveakidney.org/
Gift of Living Donation (GOLD)	http://www.morethanamatch.co.uk/di-index.php
NBTA Living Transplant Initiative	http://www.nbta-uk.org.uk/living-transplant-initiative/

Professional Guidelines/Best Practice	
The Kidney Quality Improvement Partnership (KQIP) -transplant first initiative	https://www.thinkkidneys.nhs.uk/kquip/
UK (BTS/RA) Guidelines for LDKT (4 th Edition due January 2018) Directed altruistic organ donation	https://bts.org.uk/guidelines-standards/
KDIGO Clinical Practice Guideline on Evaluation and Care of Living Kidney Donors (2017)	http://kdigo.org/wp-content/uploads/2017/07/2017-KDIGO-LD-GL.pdf
Other authorities	
Human Tissue Authority Codes of Practice and Guidance for Independent Assessors and Transplant Teams	https://www.hta.gov.uk/regulated-sectors/living-donation-approvals
Visas and Immigration (UK Entry Visas)	https://www.gov.uk/apply-uk-visa

20th November 2017

Dear Colleagues

UK Living Kidney Sharing Schemes: Quarterly Update

Following a very successful workshop in October, it was agreed that we would provide a quarterly update about the UK Living Kidney Sharing Schemes. This will include key performance data, developments in the schemes and additional resources that are available to support clinical decision-making. The update is also an opportunity to share learning and highlight best practice across the network.

The update will accompany the newsletter to the UK living donation network and will be published in February, May, August and November each year to capture the latest performance data from the previous matching run. We will also be adding these newsletters to the www.odt.nhs.uk website so that you can access historical information too.

In this first issue, we highlight the key changes to the UKLKSS that will be implemented from January 2018. Please take note of these- there are some significant changes planned, which should benefit everyone in the long run but it is important that everyone is aware of these.

Please circulate this within your teams and let us know if you wish to see anything else in this update or if you have any queries. You can email Lisa directly at lisa.burnapp@nhsbt.nhs.uk. Finally, thank you to everyone who attend the workshop in October and contributed to the actions and outcomes from that meeting. These, together with the slides presented on the day, will soon be available on the www.odt.nhs.uk website.

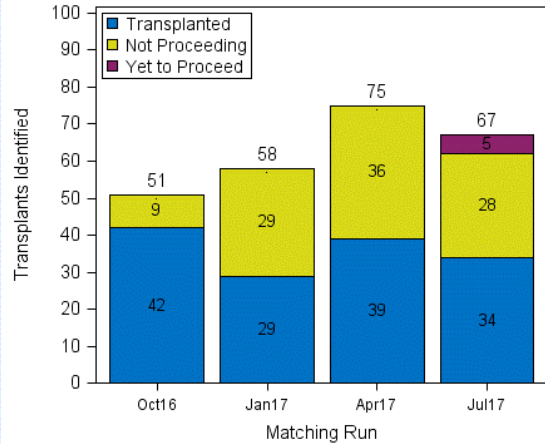
We hope that you find this useful.

Lisa Burnapp - Lead Nurse, Living Donation

Matthew Robb - Senior Statistician

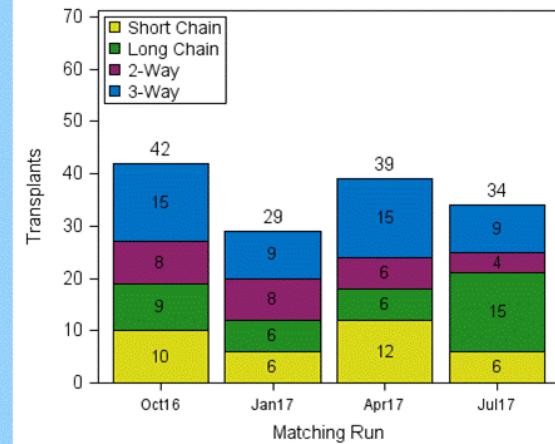
UK Living Kidney Sharing Schemes Performance Figures

Paired Donation Transplants Identified

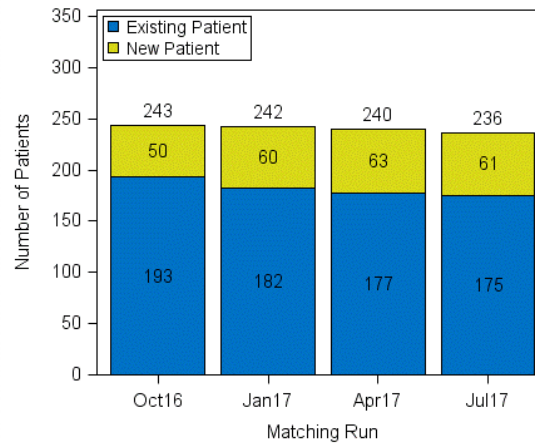


	Total May 2007 - July 2017
Pairs Registered	1922
Patients Registered	1737
Altruistic Donors in Paired Donation Matching Runs	187
Compatible Pairs Registered	83
Transplants	760

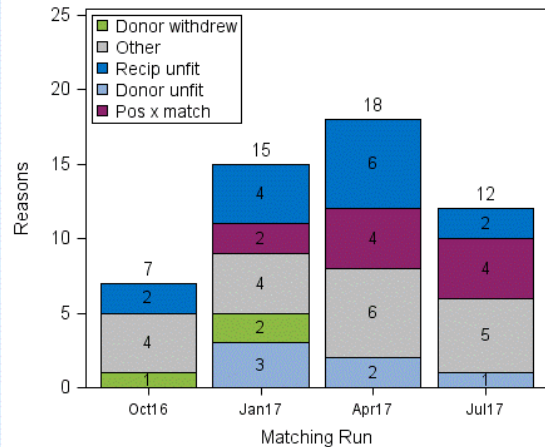
Paired Donation Transplants by Type



Patients in Each Matching Run

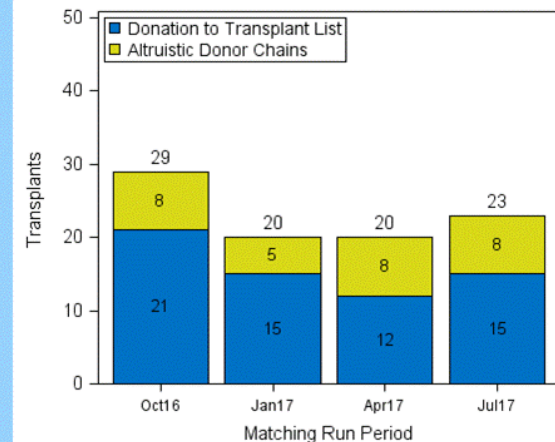


Non Proceeding Paired Donation Transplants



Note: each reason may account for multiple transplants

Altruistic Donor Transplants



UKLKSS Records	In a Matching Run
Pairs Included	284 (Jul 2016)
Patients Included	256 (Jul 2016)
Altruistic Donors Included	15 (Oct 2013)
Transplants Identified	75 (Apr 2017)
Transplants Proceeded	57 (Oct 2015)

SUMMARY OF NEW DEVELOPMENTS IN THE UK LIVING KIDNEY SHARING SCHEMES (UKLKSS) AS AGREED AT NHSBT WORKSHOP OCTOBER 2017

Development		Rationale	Implementation Date
Donor and recipient registration	Implement electronic donor and recipient registration forms	To improve: Registration and kidney offering processes Completeness and accuracy of data submitted to ODT	New forms available w/c 4 th December 2017. Paper forms accepted for January 2018 matching run All registrations to be submitted electronically for April 2018 matching run
	Inclusion of maximum donor age for recipient registration	As above	With electronic registration (April 2018)
	Inclusion of absolute GFR for all donors registered with special considerations (complex donors)	As above	By January 2018 matching run
	Removal of complex donor considerations: Right kidney Venous anatomy	As above	
Minimum data set for inclusion of complex donors and sharing donor-recipient information between transplant centres	Fixed time working group to agree criteria	To minimise manual and duplicate processes for inputting and sharing essential donor-recipient information to inform acceptance of donor offers	By April 2018
	Electronic offering system for KSS	As above	With ODT Hub Development
Revised timelines and key dates in matching run timetable including shared weeks of surgery		To: Simplify matching run timetable and improve access to KSS for all donors and recipients Minimise delays and maximise scheduled transplants within 8 weeks of matching run	Paper to Kidney Advisory Group November 2017 Publish 2018 timetable December 2017 Implement changes for April 2018
Register all non-directed altruistic donors in UKLKSS by default (unless there is a higher priority recipient on the waiting list)	All donors to be counselled early to ensure that they are informed about: Inclusion in the KSS, timelines involved, assessment and surgery schedules	To increase transplant opportunities and respond to donor wishes	January 2018 (unless previous donor preference stated) Full implementation by April 2018

	The option of their kidney being allocated to a single, higher priority recipient on the waiting list		
Quarterly UKLKSS bulletin	To be circulated to the LDKT network	To inform the network about latest statistics, performance and updates in the UKLKSS and support best practise	November 2017 (then quarterly: February, May, August each year)
Revise existing decision-making tools and resources and update www.odt.nhs.uk website		To support clinical decision-making and increase utilisation of the UKLKSS	From November 2017, then on-going. Updated existing UKLKSS transplant calculator by June 2018
New incident reporting methods	Implement on-line survey monkey to report non-proceeding exchanges	To improve data collection, inform immediate modifiable actions and inform quarterly UKLKSS bulletin	January 2018
	Communicate revised reporting categories for critical incident reporting within the UKLKSS**	To share learning and ameliorate risk within the UKLKSS	January 2018

**** Reporting Criteria for Critical Incidents (awaiting publication on www.odt.nhs.uk website)**

The following events must be reported to ODT on-line at <https://www.odt.nhs.uk/odt-structures-and-standards/governance-and-quality/tell-us-about-an-incident/>. These apply to all incidents that occur involving living donors and the recipients of living donor kidneys:

- **Early death** of donor or recipient (at time of surgery or within 3/12 post surgery)
- **Failed retrieval or implantation** of donated organ (e.g. due to damage or technical difficulty; donor adverse event)
- **Recipient misses out on a transplant** whilst a UKLKSS exchange is in progress (either simultaneous or non-simultaneous surgery)
- **Early transplant failure** (implantation to 4/52 post-transplant)
- **Damage** to donated organ
- **Non-adherence to Standard Operating Procedure for packaging and transportation** of unaccompanied organs
- **Kidney failure in the donor** within 3/12 of donor nephrectomy
- **Any unexpected or incidental finding** that others may learn from