

December 2021 • Issue 14

UK LKD Network Newsletter

INTRODUCTION

Dear Colleagues,

Welcome to the Winter Network Newsletter and another opportunity for us to acknowledge the phenomenal collective effort that has supported the recovery of living donor kidney transplantation throughout this year.

In this edition, with the kind permission of the centre involved, we include a 'Spotlight' on lessons learnt following a critical incident. We also include the recent Kidney Advisory Group update and UK Living Kidney Sharing Scheme performance data, which we would encourage you to read alongside the upcoming events and resources sections for things of interest 'beyond COVID-19' - we hope to see many of you at the Network Meeting in April 2022 in Birmingham if not before. In the meantime, we all wish you a peaceful Christmas and a happy and safe New Year!



Latest News and Updates

The following can be accessed via links:

- The latest UK Living Kidney Sharing Scheme performance figures:
<https://nhsbtbde.blob.core.windows.net/umbraco-assets-corp/25501/uklkss-quarterly-performance-figures.pdf>
- KAG Living Donor Kidney Transplantation update:
<https://nhsbtbde.blob.core.windows.net/umbraco-assets-corp/25500/kag-ldkt-november-2021-update-lburnapp.pdf>

Ongoing pandemic issues

In this edition we have included the latest update report which was submitted to KAG in November, and the latest Kidney Sharing Scheme report. We have also listed a selection of resources re. COVID-19 further below which you can access via the links.

Spotlight: Lessons Learnt

EARLY DEATH OF A LIVING DONOR - ARE THERE LESSONS TO BE LEARNT?

The death of a living donor is a rare but devastating occurrence and significantly affects those directly involved - the recipient, family members and local clinical team. It also impacts on the wider transplant community and the UK living donation programme. An unexplained death in an apparently healthy, younger person with no previous comorbidities, is particularly difficult.

A living donor in their twenties donated a kidney so that their recipient could receive a transplant through the UK Living Kidney Sharing Scheme (UKLKSS). The recipient was successfully transplanted, and the donor surgery and recovery were uneventful. The donor was discharged home two days following donation, recovering well from surgery and with no complaints.

The donor died suddenly at home 8 days following donation. At the request of the transplant centre, NHSBT performed an external review to support the team in identifying any lessons learnt, areas for improvement and shared learning. The review was undertaken a week later with broad clinical and management representation from the local team.

The focus of this newsletter is to share the learning from that review in relation to strengthening the process.

WHAT HAS BEEN LEARNED?

The living donor kidney programme in the centre involved in this case is an exemplar for best practice in all aspects of team-working and living donor care, management and follow-up. The local team highlighted the benefit of the external review process, finding it both supportive and helpful in endorsing local best practice and credibility for the living donor programme. Whilst the external review group did not identify any recommendations that would have prevented this death, it was agreed that some areas could be strengthened. These are relevant to everyone involved in living donor transplantation and clinical teams are encouraged to consider the following recommendations within their own areas of practice:

1. **Ensure that the surgical consent process is clearly documented to** accurately reflect any information provided and verbal discussion with the donor.
2. **Ensure that donor discharge from hospital and donor follow up is supported with detailed information, clear lines of referral within the team and includes:**
 - a) Engaging key supporters of the donor, including where appropriate the living donor recipient, to reinforce essential information and discharge advice.
 - b) Using a template leaflet for more detailed, explicit discharge information that donors need to know about with stronger emphasis on:
 - Prompt reporting and significance of all symptoms, even those which appear subtle and generalised
 - Clear advice about identifying key supporters, risks and possible complications
 - Appropriate action to take if donors feel unwell at home

NHSBT has committed to produce such a leaflet with input from clinical colleagues, previous donors and family members and representation from different demographic groups to ensure that messages are clear and appropriate for all people. The aim will be to produce this within the next 3-6 months.
3. **Ensure clear lines of referral within local clinical teams** so that any concerns raised about a donor's progress to staff by the donor themselves or someone close to them are immediately referred back to the living donor coordinator team.
4. **Engagement from all clinical teams to capture UK wide Donor Reported Experience Measure (DREM) and Donor Reported Outcome Measure (DROM)** in the NHSBT UK Living Donor Registry to identify and inform future areas of improvement in donor care, including donor follow-up.
5. **In a case of this kind, clinical teams are encouraged to liaise with local Coroners to reduce delay in the availability of histology findings and confirmation of outcome/s from a subsequent inquest** to ensure as much clarity as soon as possible, closure for everyone involved and provide reassurance for the benefit of the local living donation programme and across the UK.

'Save the Dates':

UK LKD Network Meeting – Wednesday 27th April 2022, 10am – 5pm

We are looking forward to holding this meeting face to face. Please let us know if you have any ideas for the meeting and email them to trudy.monday@nhsbt.nhs.uk

The 'first announcement' and 'registration opening' will be communicated in January 2022.

British Transplantation Society:

50th Anniversary Congress, 2nd – 4th March 2022, at the International Convention Centre (ICC), Belfast

Resources:

COVID-19: For latest information about the pandemic vaccination FAQs and winter pressures documents:

NHSBT: <https://www.odt.nhs.uk/deceased-donation/covid-19-advice-for-clinicians/>

BTS: <https://bts.org.uk/information-resources/covid-19-information/>

UK Kidney Association (UKKA): <https://renal.org/health-professionals/covid-19>

Donor-recipient information/organisations:

NHSBT living donor information: <https://www.organdonation.nhs.uk/become-a-living-donor/>

Patient information area: <https://www.nhsbt.nhs.uk/organ-transplantation/>

Kidney Care UK: <https://www.kidneycareuk.org/news-and-campaigns/coronavirus-advice/>

Please see the links below to the 'Kidney Matters' magazine for Autumn 2021, featuring the UK Living Kidney Sharing Scheme, and Winter 2021, featuring a celebration of black kidney donors throughout Black History Month:

<https://www.yumpu.com/en/document/read/65813601/kidney-matters-issue-14-2021>

<https://www.yumpu.com/en/document/read/65980591/kidney-matters-issue-15-winter-2021>

National Kidney Federation: <https://www.kidney.org.uk/news/coronavirus-latest-information-and-advice>

Give a Kidney: <https://www.giveakidney.org/>

GOLD: <http://giftoflivingdonation.co.uk/>

Recent Publication:

Patient information about living donor kidney transplantation across UK renal units: A critical review

This paper describes a national audit (54% centres participated) on patient information leaflets looking at inclusion of relevant information, readability score and cultural aspects. You can access key findings and conclusions in the full paper at this link: <https://onlinelibrary.wiley.com/doi/pdf/10.1111/jorc.12404>

Please contact us if we can help or support you in anyway.

- Lisa Burnapp - Associate Director- Living Donation and Transplantation - lisa.burnapp@nhsbt.nhs.uk
- Caroline Wroe - Chair of the UK LKD Network - caroline.wroe@nhs.net
- Katie Vinen - UKKA Representative - katie.vinen@nhs.net

In-coming Co-Chairs, April 2022

- Colin Geddes - UK LKD Network Co-Chair, UK Kidney Association (UKKA) Lead - colin.geddes@ggc.scot.nhs.uk
- John Stoves - UK LKD Network Co-Chair, Clinical Lead Bradford Teaching Hospitals and KAG Representative for Non-Transplanting Centres - john.stoves@bthft.nhs.uk