

September 2021 • Issue 13

UK LKD Network Newsletter

INTRODUCTION

Dear Colleagues,

In this edition of our 'Network News' we are delighted to introduce our new Co-Chairs, Colin Geddes and John Stoves who will work alongside Caroline Wroe and Katie Vinen until they formally handover in the Spring. We also update you on new initiatives and latest activity. Given the disruption of the past 18 months, it is remarkable that living donor kidney transplantation happened at all - very many thanks to everyone who played a part in this. We hope that you all managed to enjoy a well-deserved break over the summer.

New Network Co-Chairs

A warm welcome to the two new UK LKD Network Co-Chairs:

Colin Geddes Co-Chair, as the UK Kidney Association (UKKA) Lead



I have been consultant nephrologist at the Glasgow Renal and Transplant Unit since 2000 and lead clinician since 2014. I have a special interest in transplant nephrology and living donor work up and have been lead nephrologist on the Scottish Living Donor Transplant Working Group since 2014. I am an elected member of the UKKA Council and member of the Scottish Renal Association Executive.

John Stoves Co-Chair, Renal Clinical Lead for Yorkshire and the Humber Strategic Clinical Network



As Transplant Lead in Bradford I have led on a number of service development/QI initiatives, including the NHS Kidney Care Improving Access to Renal Transplantation project. As Clinical Lead for Yorkshire and the Humber Renal Network in 2013-17, I set up and led a regional transplant forum with a focus on quality improvement and MDT/patient involvement, including promotion of organ donation in BAME communities. Currently I am working with Dr Sunil Daga and qualitative research colleagues to explore aspects of decision making in living donor transplantation.

UK Living Kidney Sharing Scheme (UKLKSS) Performance Figures

We have included the latest performance summary from the UKLKSS, which includes the April 2021 matching run. Given the constraints within programmes during the pandemic, this shows a remarkable

commitment to keeping patients transplanted through the scheme when it was available. Thank you for your continued support. To access this data, please see the link below:

<https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/24613/uklkss-quarterly-performance-figures.pdf>

Latest News and Updates

A New UK Organ Donation and Transplantation Strategy

June 2021 - The new strategy – ‘*Organ Donation and Transplantation 2030: Meeting the Need*’ was published on 1st June and sets out a 10-year vision for both deceased and living donor transplantation. View strategy document here: <https://www.odt.nhs.uk/odt-structures-and-standards/key-strategies/meeting-the-need-2030/>

The Secretary of State for Health and Social Care has tasked a newly appointed Organ Utilisation Group, Chaired by Prof. Stephen Powis, to focus on the future provision and sustainability of transplantation services in England but, with a UK-wide focus. The aim is to publish recommendations in the Spring. There is a programme of stakeholder engagement, calls for evidence and requests for input planned over the next few weeks and months so watch this space and your inboxes for the opportunity to contribute. More information is available here: <https://www.odt.nhs.uk/odt-structures-and-standards/clinical-leadership/organ-utilisation-group/>

Living Donation Digital Transformation - UKLKSS

July 2021 - NHSBT Board approved the use of just over one million pounds to implement the first phase of this project, focusing on the UK Living Kidney Sharing Scheme (UKLKSS). The aim is to remove paper forms and manual processes from the administration of the UKLKSS. This is a large, complex project and it is early days, but detailed design work is already in progress. We will keep you updated with progress in future Newsletters. Further development of the UKLKSS matching algorithm and improved registration and follow-up processes for all living donors are planned for future phases of the transformation project, subject to available funding. We will keep you updated with progress. Any queries, please contact lisa.burnapp@nhsbt.nhs.uk

Writing to Living Donors - Launch of a new initiative



**Considering writing to your living donor?
We are here to support you.**

nhsbt.nhs.uk/writing-to-your-living-donor

NHS
Blood and Transplant



September 2021 - NHSBT has developed new resources to support recipients of anonymous living donations (from non-directed altruistic donors or within the UK living kidney sharing scheme) who wish to write to their donors but find it difficult to know what to say or how to put their feelings into words. The initiative for recipients of deceased donor organs has also been re-launched, with clear guidance for professionals and transplant recipients about where communications should be sent and how to manage them. The official launch on 1st September 2021 coincided with World Letter Writing Day and patient groups and key kidney and liver charities were briefed via a webinar.

Recipient guidance and resources, including a short film ‘*Dear Living Donor*’ film, can be accessed via a dedicated webpage at www.nhsbt.nhs.uk/writing-to-your-living-donor. The film is also featured on a new playlist on YouTube at www.youtube.com/playlist?list=PLjI4wHu2TagNRfR7-XfXAAQjUZJJBOh6Dq. You can add the logo and link to the new webpage to your **Email signature** using this hyperlink: <https://www.extendoffice.com/documents/outlook/1313-outlook-add-link-to-signature.html>

For professionals, we have produced cards that can be sent on behalf of the transplant or clinical team if you wish to send your own thank you. This was inspired by an initiative implemented by the living donor team in Sheffield who gave permission for us to adopt their ‘daisy chain’ original to roll it out for everyone.

To start you off, introductory packs of **daisy chain cards** and **printed flyers** for recipient discharge packs have been provided to each transplant centre. These can be re-ordered as required via leaflets@nhsbt.nhs.uk.

Details will follow soon via email about a **‘Writing to living donors – information webinar’**, via Zoom. See the information in the ‘Save the Date’ section further below.

Monitoring and feedback

Please send us your comments and feedback once you start to use the new resources and we ask living donor co-ordinators in transplant centres to keep a record of the number of:

- Cards sent out to donors from teams
- Communications from recipients of living donor organs that are passed on to their donors

Finally, grateful thanks to Jen Hobbs and colleagues in NHSBT Marketing and Communications for producing the resources and to everyone who worked alongside me on the working group, without whom this would not have been possible:

Jen Hobbs (Marketing and Communications, NHSBT), Helen Dobson (Newcastle), Caroline Basarab-Horwath (Sheffield), Jen Lumsdaine (Scotland), Jan Shorrocks (Give a Kidney charity), Celia Kent (Living Donor), Ewen Maclaen (Transplant Recipient and Advocacy Service, Kidney Care UK)

Lisa Burnapp, Working Group Chair

Community Investment Scheme – Living Donation

Over the last 3 years the Community Investment Scheme, run by NHSBT, has funded community and faith/belief organisations to positively engage Black, Asian, Mixed Race and minority ethnic communities in deceased organ donation and more recently, blood donation. Building on the success and learning from the Living Transplant Initiative, NHSBT has incorporated living donation into the Community Investment Scheme, to continue to promote living donation across the UK through grass roots organisations by increasing awareness, addressing misinformation and barriers, and driving behaviour change in a culturally sensitive way.

Funded projects will aim to start in January 2022 following completion of a successful application process, which is in progress. For more information visit <https://www.nhsbt.nhs.uk/livingscheme/>

Here is a video about the scheme: <https://drive.google.com/file/d/1BUZx-Q31VfAUNZfQfBh-5qNxWIMt8LSB/view?usp=sharing>

Any queries, please contact Living.Donation@nhsbt.nhs.uk

‘Save the Dates’:

Writing to living donors - Information webinar, via zoom, date TBC

Previously circulated by email, this webinar is designed to introduce the new initiative and provide guidance about how to use and access resources and information. Aimed at all healthcare professionals but particularly relevant for living donor and recipient co-ordinators who manage communications between anonymous living donors and the recipients of their kidneys.

UK LKD Network Meeting – Late April/early May 2022, date TBC

We hope to hold this meeting face to face and have delayed it until later in the Spring to avoid any additional winter pressures related to COVID-19. Please let us know if you have any ideas for the meeting and email them to trudy.monday@nhsbt.nhs.uk We start planning next month and will confirm a date as soon as possible.

Useful Resources

COVID-19 resources – Latest resources and guidance accessed via the following links:

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

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

RA: <https://renal.org/health-professionals/covid-19>

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

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

Other resources:

Donor-recipient Information: <https://www.organdonation.nhs.uk/become-a-living-donor/> (Kidney concertina)

UK LKD Network: <https://www.odt.nhs.uk/living-donation/uk-living-kidney-donation-network/>

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

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- **Caroline Wroe - Chair of the UK LKD Network -**
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- **John Stoves - UK LKD Network Co-Chair,**
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