NHS BLOOD AND TRANSPLANT
ORGAN AND TISSUE DONATION AND TRANSPLANTATION

MINUTES OF THE TWENTY-NINTH KIDNEY PAEDIATRIC SUB-GROUP MEETING HELD AT 11AM ON MONDAY 10 OCTOBER 2022 VIA MICROSOFT TEAMS

PRESENT:

Dr Helen Jones, Paediatric Nephrologist Evelina London Children's Hospital (Co-Chair)
Dr Richard Battle, BHSI Rep.
Dr Mairead Convery, Consultant Paediatric Nephrologist, Belfast
Ms Rebecca Curtis, Statistics & Clinical Research, NHSBT
Mr Martin Drage, Consultant Transplant Surgeon, Evelina & GOSH
Dr Jan Dudley, Consultant Paediatric Nephrologist, Bristol
Miss Anusha Edwards, Consultant Transplant Surgeon, Bristol
Dr Shuman Haq, Consultant Paediatric Nephrologist, Southampton
Dr Colin Higgins, Medical Trainee Rep, GOSH
Dr Jon Jin Kim, Consultant Paediatric Nephrologist, Nottingham
Prof. Stephen Marks, Consultant Paediatric Nephrologist, GOSH
Dr Mordi Muorah, Consultant Paediatric Nephrologist, Birmingham
Dr Charlie Pickles, Paediatric Nephrologist, Newcastle
Dr Tracey Rees, Chief Scientific Advisor, NHSBT
Mr Vlad Shumeyko, Consultant Transplant Surgeon, Glasgow
Mr Afshin Tavakoli, Transplant Surgeon, Manchester
Dr Yincent Tse, Consultant Paediatric Nephrologist, Newcastle
Ms Julie Whitney, Head of Service Delivery, Hub Operations
Professor Anthony Wrigley, Lay Member

IN ATTENDANCE:

Ms Alicia Jakeman, Clinical & Support Services, NHSBT

APOLOGIES:

Dr Christian Brix, Consultant Paediatric Nephrologist, Leeds
Dr Martin Christian, Consultant Paediatric Nephrologist, Nottingham
Dr Eric Finlay, Consultant Paediatric Nephrologist, Leeds
Dr Richard Holt, Consultant Paediatric Nephrologist, Liverpool
Dr Ben Reynolds, Consultant Paediatric Nephrologist, Glasgow
Mr Sam Turner, Consultant Transplant Surgeon, Bristol
Mr Alun Williams, Consultant Urology and Transplant Surgeon, Nottingham (Chair)

		ACTION
1	**Declarations of interest in relation to the agenda**	
	There were no declarations of interest.	
2	**Minutes of the meeting held on 04 July 2022 - KAGPSG(M)(22)3**	
2.1	**Accuracy**	
	A correction to R Battle's title was noted. The minutes were agreed as a true and accurate record and ratified.	
2.2	**Action points - KAGPSG(AP)(22)2**	
	All action points had been completed or were included on the agenda. **AP1 Update on non-favourably matched paediatric grafts** Item 8.2 on the Agenda. There have been no further paediatric non-favourably HLA-mismatched kidney transplants performed.	

		ACTION
	R Battle to bring a copy of BHSI guidelines to the next KAGPSG meeting as these are still under review. To be discussed under AOB. **AP2 KAGPSG Membership** A Edwards advised that she had received an EOI from a Surgical Trainee and she will ask him to send the EOI to A Williams. H Jones welcomed C Higgins and V Harkins as Medical Trainee Reps. H Jones and Y Tse are appointed as KAGPSG Vice Chairs. **AP3 Paediatric activity in the new kidney offering scheme** To be discussed under AOB. **AP4 Paediatric dialysis capacity issues** To be discussed under Item 8.2 on the Agenda, attached for information only. Since the meeting, R Curtis has looked at how to split the data by referral centre rather than transplanting centre. This is received a year in arrears as it is matched using UK Renal Registry data and therefore can't be done in real-time. The Group confirmed that would still like to see this data. R Curtis will add to the paper for the next meeting. **New monitoring process** To be discussed under Item 5 on the Agenda. **AP5 Any other business** Transplantation from 50 years and over donors to be discussed under AOB.	**A Edwards** **R Curtis**
2.3	**Matters arising not separately identified**	
	There were no matters arising.	
3	**UK renal transplantation status during COVID-19**	
	3.1 Centres operating All centres provided an update; Belfast open for deceased and living donation GOSH fully open, 39 patients transplanted in the last year. There is an increase in COVID-19 numbers in London with an under-reporting of COVID-19 in the Community. Evelina are fully open, increased COVID cases with one post-transplant inpatient with COVID currently. Suspended cases due to COVID. Southampton are fully open but have experienced nurse shortage due to COVID and have suspended cases due to patients having COVID. Birmingham recently cancelled a living transplant due to the donor having COVID. Manchester is fully open with a case recently cancelled due to transfusion blood not being available in preparation for their operation. This will hopefully be done in the next two weeks. Newcastle open for living and deceased transplants. Due to staffing issues their ward has been closed, causing issues for patients leaving PICU. Glasgow are fully open, they didn't close and managed to clear their waiting list during COVID. Recently two live donors tested positive but the transplants proceeded after eight weeks. It has been difficult to plan ahead due to staffing issues. Nottingham are not experiencing any issues. Leeds were not represented at the meeting. Bristol are fully up and running. Members discussed what their patients and families are doing in terms of shielding and isolating, having reported cancellation of living donor transplants. Some families aren't able to shield for six weeks' post-transplant hence the centres are seeing COVID cases. All families are encouraged to shield where able but rules are relaxed	

		ACTION
	now and it's very difficult to get a PCR test. Members questioned the validity of Lateral Flow test results. S Marks advised that the manuscript using national data is almost ready for submission, looking at the outcomes of immunosuppressed children after kidney transplants, who got COVID-19, with most patients doing quite well with minimal hospital admissions. Discussion in group as to whether this standing agenda item needs to remain, it will until further notice due to incoming winter period.	
4	**Centre specific organ decline rates - KAGPSG(22)10**	
	R Curtis presented regular paper established to look at decline rates over time. It was noted that offering for Tier B patients was centre-based during March 2020 and June 2020. Decline rates for DBD showed rates from January 2017 to June 2022 ranging from 26% to 59%. The decline rate is hovering around 40% mark nationally. With DCDs there is more of a variation and fluctuation which is hopefully settling. R Curtis asked centres to consider ways to minimise their offer decline rates within their individual centre. H Jones acknowledged this would provide opportunities to learn from those centres that decline less. H Jones asked if offers are being declined for patients who are a poor match and who are sensitised. At The Evelina they now have a formalised process within their Clinical Governance meetings looking at declines, acknowledging that it is difficult to decline kidneys for those cases that are not straight forward. M Muorah advised that he had just been emailed to state that an offer had been declined due to the donor having Meningitis, he asked why offers are received for those patients with contra-indications. It was noted that past medical history isn't in the list of contra-indications. J Whitney shared the link to the clinical contraindications policy for organ donation that the specialist nurses follow; https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/25962/pol188.pdf R Battle feels that mis-match grades could be potentially involved in the reason for decline. S Marks advised that K-QUIP have got a program which is ongoing with different streams of quality improvement. S Marks & J Dudley have potential projects looking at harmonisation data and declined offers. He asked if all centres were behind the declined offers audit and advised that he would like to look at the decline data in another year, acknowledging that everyone is really busy and the trainees and nurse specialists do not have time for data collection when they know of a declined offer. R Curtis advised that NHSBT Stats. have also thought of completing this audit now that the scheme has changed. H Jones asked members to email herself, A Williams or A Jakeman to advise of their centre's pressures with the data collection and provide an indication of what they are doing for the harmonisation project. A Tavakoli advised that at Manchester the paediatric offers are made through the adult centre, due to this an offer was missed. To be discussed further off-line. M Drage asked if the national decline data could be audited for those organs that were then transplanted in an adult, to be shared with the Group for shared learning. This will be added as an Agenda Item for the next meeting. A Tavakoli suggested this be presented at the next surgical or transplant challenge meeting. This discussion highlighted that the process varies over Centres, with not all patients meeting with the Transplant Surgeons annually. M Drage advised that there is a requisite nationally, to hold these meetings. It was noted that these meetings are useful to discuss and review mismatch criteria. H Jones advised that following the discussions with family members on the offers sometimes prompts people to come forward as living donors. She will send an email around to members to see if anyone is keen to be involved in the project.	**All** **A Tavakoli/ J Whitney** **All** **A Jakeman** **H Jones**
5	**Monitoring Report - KAGPSG(22)11**	

		ACTION
	R Curtis presented a new graphical method for monitoring paediatric activity in the kidney offering scheme. This will be added into future monitoring reports. A control chart method is used with a baseline level established and 3- and 2- standard deviations above and below this illustrated. Separate charts for offers and transplants to paediatrics are presented. Charts are used to identify if at any point the lower limit line is crossed to recognise if this is possible deviation from the baseline, looking at quarterly data from October 2019 to date. The thresholds have not been crossed after an initial expected settling in period due to a backlog of difficult to match patients being transplanted with the new scheme.	
6	**Quality improvement & academic pursuits**	
6.1	**ISpy** JJ Kim advised that the COVID antibody study paper was submitted to CKJ but did not pass the Editors first-time round and will be resubmitted. He shared the data with the Group.	
6.2	**Molecular HLA Study** JJ Kim advised that 324 samples have been collected and for those in the HLA Group, he will be looking at the electrostatic mismatch score. He Is looking at epitope matching which is very effective in children. NHSBT does the eligibility screening, sending the list to centres. The data is not collected yet and he is starting to produce the REDCap database. The aim is to receive 500 samples and encourages centres to get in touch with the local PI to come on board.	
6.3	**HLA and donor quality** The research questions is; How does donor quality and HLA mismatch affect long term kidney transplant survival? The graft survival data on 20-year outcomes, showed the median outcome is 19 years on 1st kidney transplants between 1/1/2000 and 31/12/2004. JJ Kim presented survival data on Watson KDRI data and KDRI Groups. R Curtis and JJ Kim will discuss this data offline as further discussion is needed around the use of the KRRI needed. Need to further understand the differences in risk groups for children and adults with all the same circumstances except age. The data analysis on the HLA mismatch groups is complete. JJ Kim was advised to change the word Caucasian to White under Recipient ethnicity, in line with how NHSBT collects this data.	**R Curtis/ J J Kim**
6.4	**Harmonisation Project & Supplementary Forms** S Marks discussed the agreement that as a renal transplant community, to try and harmonise immunosuppression in the 13 paediatric nephrology units, with 10 doing transplantation. The two-page supplementary follow-up form was shared on-screen. J Whitney confirmed that some follow-up forms are sent out electronically and some digitally. The sharing of the supplementary forms will match the way in which the centres fill out other forms. J Whitney shared the ODT Hub Dashboard with the Group, showing compliance with the completion of Transplant record follow-up forms and HTA-B return rates. J Whitney will explore whether this should be split into Paediatric and Adult Data. J Whitney confirmed that she would be able to provide, by transplant centre, which forms are paper, which are digital, who correspondence and chase emails are sent to and at what point in the pathway.	**J Whitney/ R Curtis**
6.5	J Dudley provided an update that the Smaller recipients paper is almost ready for submission, pending response from Chloe Brown. When all comments are received it will be submitted to Transplantation. R Curtis will ask Chloe Brown to email J Dudley.	**R Curtis**
6.6	J Dudley provided an update on the DCD paper that S Marks is leading on. It was turned down but will be resubmitted.	
6.7	S Haq advised that his Anuric Bladders Project started one week ago. S Haq has contacted centres with the updated questionnaire, asking for them to identify someone who will be doing the data collection.	

		ACTION
6.8	H Jones provided an update on the Impact of C0VID-19 lockdown on transplantation in the UK abstract, which has been submitted to IPTA.	
6.9	H Jones provided the background regarding project looking into donation from donors aged 50 and over. The donor age threshold increased from 50 to 60 for deceased donor kidney donation to paediatrics on 16th September 2021. R Curtis will discuss the data with C Higgins out of this meeting. Looking at donor data for the over 50s, living and deceased donors and how much data there is to be able to analyse outcomes. J Dudley suggested looking at decline offers for this group, should centres receive an offer from an over 60 donor and if this influences decisions as to whether the centre accepts the offer or not.	**R Curtis/ C Higgins**
6.10	J Dudley advised that collecting monthly dialysis figures, by emailing Centres 14th of each month with a link to MS Forms, is working well. J Dudley updates the Group on a monthly basis with the graph which shows a downward but then stabilising trend in the numbers on dialysis since end of last year. There are around 250 patients on dialysis, which is about 20% above previous baseline. The 'median waiting time' figure provided by NHSBT shows at a snapshot in time, the median waiting time points and includes dialysis time as well as suspended time. RC urged that this figure in particular be interpreted with caution due to the definition and due to the fragile nature (i.e., due to small numbers on the list this figure can be greatly impacted by only small changes to the list). This is not the most accurate way to look at median waiting time. This value is triangulated with offers data, numbers of transplants and the number of people on dialysis. The Group agreed that this data should continue to be collected. The twelve months data on dialysis numbers will be presented at the next meeting.	
7	**PTLD**	
	S Marks advised that a student looked at the NHSBT data, doing some abstract submissions and is currently writing up their publication. He feels that it is worthwhile relooking at as some of the granular details have changed and thinks it's potentially something the Group can do with harmonisation. In a few more years, once there is more harmonisation data and outcome data, they will link better.	
8	**For Information only**	
8.1	**Centre specific transplant list and transplant activity - KAGPSG(22)12**	
8.2	**Update on non-favourably matched paediatric grafts - KAGPSG(22)13** There have been no further paediatric non-favourably HLA-mismatched kidney transplants performed.	
9	**Any other business**	
	The Group discussed Meeta Malik's email, on patients at Nottingham, one pre-transplant, one post-transplant who have got EBV viraemia. Some centres confirmed that they give Rituximab post-transplant, she asked how many Centres give Rituximab and at what level for high viral load carriers. They also discussed a case of a patient on dialysis for 3 years, with EBV viraemia first detected in 2021 during COVID infection. H Jones advised that The Evelina monitors the EBV viral load, not giving Rituximab. The group agreed not to give Rituximab pre-transplant. J Dudley asked for an HLA presentation/discussion at the next meeting, the four HLA mismatch groups and the use of the wording unfavourably. To be added to the agenda for the next meeting to make sure that all centres are on the same page in terms of what they should be listing for and what language means. R Curtis will look at the language used with clarification around favourable and non-favourable phrasing.	**A Jakeman** **R Curtis**

		ACTION
	R Battle provided a verbal update on the updated BHSI & BTS draft antibody guidelines, on the questions of the limiting of a DR mismatch during the first year. It details the considerations that are important in terms of future sensitisation. The tools don't allow for the mismatch grade to be entered. After the next draft they will be placed on the BTS website for consultation. R Battle will advise A Jakeman so that group members can comment.	**R Battle/ A Jakeman**
10	**Date of next meeting - TBC** H Jones proposed that the next meeting will be held on a Friday, suggesting Friday 20th January 2023. The Spring meeting will be held face-to-face. Y Tse suggested meeting the day after the UKKA BAPN winter virtual meeting, J Dudley agreed that 27th or 28th January 2023, or running KAGPSG as a parallel session would result in a good attendance.	