NHS BLOOD AND TRANSPLANT
ORGAN AND TISSUE DONATION AND TRANSPLANTATION

MINUTES OF THE THIRTY SECOND MEETING OF THE KIDNEY ADVISORY GROUP PAEDIATRIC SUB-GROUP HELD ON FRIDAY 24 NOVEMBER 2023 10:00 - 15:00 VIA MICROSOFT TEAMS

ATTENDEES

Helen Jones	**Deputy Chair, Paediatric Nephrologist, Evelina**
Martin Christian	Consultant Paediatric Nephrologist, Nottingham
Mairead Convery	Consultant Paediatric Nephrologist, Belfast
Martin Drage	Consultant Transplant Surgeon, Evelina & GOSH
Jan Dudley	Consultant Paediatric Nephrologist, Bristol
Anusha Edwards	Consultant Transplant Surgeon, Bristol
Shuman Haq	Consultant Paediatric Nephrologist, Southampton
Colin Higgins	Medical Trainee Representative, Evelina
Joanna James	Transplant Coordinator, Leeds
Jon Jin Kim	Consultant Paediatric Nephrologist, Nottingham
Stephen Marks	Consultant Paediatric Nephrologist, GOSH
Omar Masood	Consultant Transplant Surgeon, Leeds
Mordi Muorah	Consultant Paediatric Nephrologist Birmingham Children's Hospital
Charlie Pickles	Consultant Paediatric Nephrologist, Newcastle
Rommel Ravanan	KAG Chair
Ben Reynolds	Consultant Paediatric Nephrologist, Glasgow
Shaminie Shanmugaranjan	Statistics and Clinical Research, NHSBT
Mohan Shenoy	Consultant Paediatric Nephrologist, Manchester
Vlad Shumeyko	Consultant Transplant Surgeon, Glasgow
Julie Whitney	Head of Service Delivery, Hub Operations, NHSBT
Yincent Tse	Deputy Chair & Consultant Paediatric Nephrologist, Newcastle
Pallavi Yadav	Consultant Paediatric Nephrologist, Leeds

IN ATTENDANCE

Alicia Jakeman	Clinical & Support Services, NHSBT

APOLOGIES

R Battle, C Brix, J McAllister, M Ognjanovic, T Rees, A Tavakoli, K Tyerman, A Williams, A Wrigley

ITEM		ACTION
1	**Declarations of interest in relation to agenda**	
	There were no declarations of interest in relation to the agenda.	
2	**Minutes of the meeting held on 02 May 2023 - KAGPSG(M)(23)2**	
2.1	**Accuracy**	
	Members advised of inaccuracies to the Minutes. Amendments to the Minutes were made: Glasgow were stated as not present for Agenda Item 3.1 but later joined the meeting.	

	Meeting. Under Item 11, Royal Free should be amended to Southampton. J Dudley advised of the discrepancy with recording median waiting times, this highlighted the different ways of reporting median waiting times. This will be discussed with S Shanmugaranjan outside of the meeting, in order to provide consistent data going forward.	
2.2	**Action points arising - KAGPSG(AP)(23)2**	
	AP1 - 2019 Kidney Offering Scheme and paediatric transplant activity - will be carried over to the next meeting. **AP11 - AOB** - L Burnapp will be invited to the next meeting to provide further clarification on the correct way to register recipients on the living pathway. **AP11 - AOB** - H Jones and M Drage provided further information on the pre-transplant Haemoglobin audit data and Clinical Guidance developed at the Evelina for anaesthetists, including Urea and Haemoglobin levels pre-transplant.	**A Jakeman**
2.3	**Matters arising not separately identified**	
	There were no matters arising.	
3	**UK renal transplantation status**	
3.1	**Centres operating**	
	All members provided updates on their Centres; Evelina are open for both living and deceased donors, with no issues. GOSH have no impacts on the unit, open for both living and deceased donors. Bristol are compromised due to the lack of deceased donor offers and issues when trying to get additional theatre slots for living donor transplants. Glasgow are open, with a low number of deceased donors and LRDs, there are no major issues or challenges. Leeds advised that they are receiving fewer deceased donor offers, both DBD and DCD. Southampton are open as usual. Newcastle advised that PICU capacity and ward nurse shortage might be an issue, they are open for both living and deceased donors. Belfast also advised that PICU capacity might be an issue, they are open for both living and deceased donors. Nottingham reported that there are no problems at the moment However, A Williams is on long-term sick leave and they are trying to double-up with Surgeons. Birmingham have had a number of offers for long waiters, surgical resilience remains an issue. Manchester advised that they have received a reasonable number of offers. Cardiff & Liverpool were not represented at the meeting.	
4	**Kidney offer decline rate audit - KAGPSG(23)10**	
	Shaminie Shanmugaranjan presented the regular paper, J Dudley asked for Table 1, Paediatric donor kidney offer decline rates by kidney transplant centre, to be broken down into more detail, to explain why centres are out of the confidence limits. H Jones asked for the offer detail in Table 2, Paediatric DBD kidney offer decline rates by offer year where the kidney was subsequently transplanted, to be included in Table 1. J Dudley invited S Shanmugaranjan to the next KQuIP Audit meeting.	**S Shanmugaranjan** **J Dudley**
5	**Relaxation of match grades for offering - KAGPSG(23)11**	
	J Dudley advised that currently patients are listed on the national waiting list for a favourably matched kidney. However, due to the massive decrease in offers since 2019, discussions were held on whether to continue to list them for a	

	favourable match. JJ Kim has recently reported on higher rejection rates and graft loss due to poorer matches. Centres reported that if they have a moderate or difficult case and are compromising the chances of an offer, a matchability score of 5 is a cut-off accepting a total of 4 mismatches. There is variability across centres as to when they relax the match points. J Dudley will create a questionnaire for dissemination to centres to record the listing of patients at first listing and subsequent relaxation, including whether they have H&I involvement in the decision making. This will also include a question on avoiding parental mismatched antigens. H Jones advised that A Williams has suggested adopting a different terminology to 'favourably' and 'unfavourably' matched to use the matchability score only.	**J Dudley**
6	**Mutual aid between centres**	
	This was discussed under Agenda Item 9.	
7	**Quality improvement & academic pursuits**	
	B Reynolds confirmed that the Outcomes in smaller children compared to larger children paper has been submitted to Paediatric Nephrology and has been accepted. The Molecular HLA project deadline for data collection will be set for March 2024. J J Kim reported that Manchester, Liverpool and GOSH are making good progress. The I-SPY paper has been published. J J Kim advised members of a multi-arm study, that French Transplant Centres have funding for. This study is looking at patient stratification and personalised medication, looking at self-DNA tests and TVIS, a viral marker and epitome marker. He suggested tagging on to the French Study to work collaboratively. S Marks advised that he has also spoken with the French Group, B Reynolds advised of the LIMIT Study that will hopefully receive funding soon. Members felt that Bio-Banks are very expensive to set up, with M Drage reporting that Edinburgh are submitting a bid for a National Recipient Biobank.	
7.1	**Micro-bladder study**	
	S Haq provided an update on the preliminary data from the Kidney transplantation in micro-bladders study, asking centres to send their data to increase numbers to over 30. He will also be contacting centres with data queries. Patients have varying level of follow-up. He confirmed that he was hoping to submit a paper for publication in the next three months and will request the outstanding data. He asked that in terms of consent, should he develop a patient information leaflet, asking patients if they are happy with the data collection. It was agreed that retrospective consent should not be sought. S Haq confirmed that the data highlighted that urethral catheters were not left in much longer than super-pubics. The main issue with these young patients was incontinence, there have been a number of patients with urinary tract infections.	**All** **S Haq**
8	**Consideration of HCV donors**	
	B Reynolds advised members that the Kidney Advisory Group had previously held conversations to increase donors to include Hep C positive donors for recipients. He asked members if these donors should be considered for a select group of paediatric patients. J Whitney advised that NHSBT do not receive the genotyping at the time of offering, they may be offered as positive and are found to be subsequently negative the next day. J James advised that Leeds accept them for adult but not paediatric patients J Whitney will contact B Reynolds to discuss this outside of this meeting.	
9	**Surgical workforce resilience**	

	H Jones advised that Birmingham and Nottingham have recently been unable to provide paediatric kidney transplantation due to the lack of surgical cover. R Ravanan confirmed that with D Manas, they have met with the CMO of one of the units along with Clinical Leads. Other Units have been approached to provide mutual aid. R Ravanan confirmed that there is significant support from Trust Leadership and that the Lead Commissioner from NHSE is keen to be involved and help with problem solving. A joint summit will be held on 15th December, via MS Teams, three representatives from each unit will be invited, to home in on the areas of focus. R Ravanan confirmed that Devolved-nation Commissioners will be invited to the meeting. Belfast and Glasgow confirmed that they are not seeking mutual aid at present. B Reynolds confirmed that Glasgow can provide dialysis support and have existing SLAs in place for various services that are provided by English trusts. All Centre representatives were asked if they were happy to provide mutual aid to those centres. All members present agreed that were keen to help. M Christian updated members that Nottingham are having issues with transplant surgeon availability. M Muorah updated members that in Birmingham Children's Hospital, they had a lack of surgeons due to sickness. They have previously had a date where they asked for help, this highlighted gaps in the service. However, they have recently helped Nottingham when they lacked surgical availability. Members felt that this will also unify work-up across centres.	
10	**For information only** 10.1 Centre specific transplant list and transplant activity report - **KAGPSG(23)12**	
11	**Any Other Business**	
	R Ravanan advised that Expressions of Interest for a new KAGPSG Chair will soon be sent to various forums. S Haq suggested a questionnaire post-harmonisation as there has been some PTLD in the last two years since the harmonisation program started. J Dudley advised that this data has been collected for two years and will be picked up in the KQuIP meetings. JJ Kim advised members that he is completing a systems thinking management course, looking at complex problems. JJ Kim suggested trying to solve the waiting list problem in Paediatrics as the subject of his dissertation. He will set up a panel and asked for volunteers. JJ Kim will send out a summary to members. Fiona Gibson, Transplant Nurse, Birmingham has asked for information on frequency of viral monitoring pre-transplant for paediatrics on-call. Members confirmed annually with Bristol and Glasgow only testing for HCV, Hep C and HIV once. Centres are not aligned with this, with M Drage advising that virology tests are repeated on patients following foreign travel at Evelina & GOSH. ****Post meeting note** M Drage was asked to clarify if he was referring to adult patients rather than paediatrics.** Membership of KAGPSG was discussed with an advert for a Medical and Surgical Trainee going out shortly, along with the appointment of a new Chair. The Terms of Reference for Advisory Groups are being reviewed by R Ravanan.	**JJ Kim**
12	**Date of next meeting – TBA**	