NHS BLOOD AND TRANSPLANT
ORGAN AND TISSUE DONATION AND TRANSPLANTATION

MINUTES OF THE THIRTY-FIRST KIDNEY PAEDIATRIC SUB-GROUP MEETING HELD AT 11AM ON TUESDAY O2 MAY 2023 VIA MICROSOFT TEAMS

PRESENT:

Alun Williams	Consultant Transplant Surgeon, Nottingham (Chair)
Christian Brix	Consultant Paediatric Nephrologist, Manchester
Martin Christian	Consultant Paediatric Nephrologist, Nottingham
Mairead Convery	Consultant Paediatric Nephrologist, Belfast
Martin Drage	Consultant Transplant Surgeon, Evelina & GOSH
Anusha Edwards	Consultant Transplant Surgeon, Bristol
Shuman Haq	Paediatric Nephrologist, Southampton
Colin Higgins	Medical Trainee Representative, GOSH
Helen Jones	Consultant Paediatric Nephrologist, Evelina (Co-Chair)
Derek Manas	Medical Director - OTDT
Stephen Marks	Consultant Paediatric Nephrologist, GOSH
Joseph McAllister	Consultant Paediatric Nephrologist, Leeds
Mordi Muorah	Consultant Paediatric Nephrologist, Birmingham
Cara Murdoch	Team Manager - OTDT
Rommel Ravanan	KAG Chair
Tracey Rees	Chief Scientific Advisor, NHSBT
Ben Reynolds	Consultant Paediatric Nephrologist, Glasgow
Matthew Robb	Statistics & Consultant Clinical Research, NHSBT
Shaminie Shanmugaranjan	Statistics & Clinical Research, NHSBT
Vlad Shumeyko	Consultant Transplant Surgeon, Glasgow
Yincent Tse	Consultant Paediatric Nephrologist, Newcastle (Co-Chair)
Chris Watson	University of Cambridge
Julie Whitney	Head of Service Delivery, Hub Operations
Anthony Wrigley	Lay Member

IN ATTENDANCE:

Alicia Jakeman, Clinical & Support Services, NHSBT
Cherrelle Francis-Smith, Clinical & Support Services, NHSBT

APOLOGIES:

Richard Battle, Jan Dudley, Jon Jin Kim

ITEM		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**	
	The minutes were agreed as a true and accurate record and ratified. Section 4.4 should read Uropathy not Neuropathy and will be amended.	
2.2	**Action points - KAGPSG(AP)(22)2**	
	All action points had been completed or were included on the agenda.	
2.3	**Matters arising not separately identified**	
	There were no matters arising.	

ITEM		ACTION
3	**UK renal transplantation status during COVID-19**	
	3.1 Centres operating All centres provided an update: Belfast are open for deceased and living donation. Bristol are fully up and running. GOSH are fully open and completed a deceased donor kidney transplant during the nursing strike, with Medical Director's approval. Evelina are fully open and reported having to move one living donor transplant date. Southampton are fully open. Birmingham reported a live donor transplant date being moved due to strikes. Manchester are fully open. Newcastle are fully open. Glasgow were not present at this time, having later joined the meeting. Nottingham are fully up and running. Leeds have completed three transplants in the last month, with their first deceased donor transplant for some time. They ran a full service during the strikes. D Manas asked if centres were experiencing issues with interpreting COVID guidance. R Ravanan confirmed that all centres should be accepting organs from COVID positive donors. Manchester confirmed that they have accepted an offer.	
4	**2019 Kidney Offering Scheme and paediatric transplant activity - KAGPSG(23)05**	
	S Shanmugaranjan presented the paper, established to look at paediatric transplant activity, waiting times and decline rates over the first three years prior to the introduction of the Kidney Offering Scheme (KOS) on 11th September 2019, compared with activity since the start of the new scheme. This replaced the Kidney Allocation Scheme, introduced in April 2006. All deceased donor kidneys are now offered using national rules through a two-tier offering sequence; Tier A – Patients with a matchability score = 10, 100% cRF or ≥7 years waiting time and Tier B – All other patients. It was noted that offering for Tier B patients was centre based between 31st March 2020 and 15th June 2020 and this data was excluded. Waiting times were approximately 200 days in the old scheme, with predictions made that this would increase to 250 days in the new scheme. S Shanmugaranjan advised that it was also predicted that paediatric transplant numbers would initially drop with the start of the new scheme but increase again by the third quarter of the scheme. The paper compares the number of offers made to paediatric patients with 328 offers before the start of the new scheme decreasing to 260 in the new scheme. Per 100 eligible donors, this drops from 12.0 to 10.1. The number of declined offers dropped from 70 between September 2016 and September 2019 to 48 between September 2019 and September 2022. Looking at the reasons for decline of named kidney offers, the numbers declined due to donor unsuitable – past medical history, dropped from 39 to 20. The paper reports the number of offers by their HLA mismatch level for the two 3-year periods prior to and since the new scheme. The percentage of level 1 offers remained similar, but level 2 offers increased from 73% in 2016-2019 to 83% in 2019-2022 of all offers. Although there was a decrease in the percentage of level 3 offers, from 22% in 2016-2019 to 7% in 2019-2022, level 4 offers increased from 0% to 4%. Looking at the quality of paediatric offers for the two 3-year periods prior to and since the new scheme for donor risk index groups, D1 to D4, the quality of offers has improved since the new scheme, with D1 donors making up 74% of donors in the new scheme compared to 56% of donors in the previous period. The waiting list demographics as at 1st September 2019 and 1st March 2023 detail an increase of 94 to 104 for patients under 18. However, paediatric patients make up the same proportion of the waiting list as before and the median active waiting time has not changed very much; from 287 days to 282 days in the final period of the report.	

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	S Marks recalled discussions at previous meetings when median times had raised from 250 to 270 days, with waiting times now increased significantly. He highlighted the issues with dialysis capacity due to the COVID pandemic and the need to improve the waiting list time for paediatric patients. R Ravanan acknowledged the concerns of KAGPSG. Within the new scheme the highly sensitised patients having been transplanted. D Manas confirmed that DCD usage in paediatrics is low and questioned whether a change is practice could increase utilisation in paediatrics. He asked whether the scheme should be monitored more frequently than annually. M Robb confirmed that the reports within this paper are also presented at KAG. Y Tse feels there are effects on the units due to dialysis capacity issues alongside the limited number of organs available for transplant. Dialysis nurse numbers should not be decreased. H Jones confirmed that an organ at the Evelina had been declined on the day of transplant as the match wasn't good enough and questioned how this offer could have been made. They also continue to monitor suspended days to ensure that patients are active on the waiting list without too much delay. Units have experienced issues where a patient wasn't well enough on the day of transplant, but some causes could have been predicted, e.g low Haemoglobin levels. C Watson advised that long waiting patients need to be ready when the offer is made but members agreed this is not always the case. A Williams advised that the KQUIP and KAGPSG discussions on organ declines should look at this in more detail and asked STATs to increase the survival data from 3 months' survival commonly reported for declines. Members confirmed that at the majority of units, the offer is made to the Surgeon first. At Bristol the offer goes to the Nephrologist first due to short-staffing of Surgical colleagues, at Glasgow the offer goes to the Nephrologist first as they wish to take the offers. R Ravanan advised that with an adult D1 kidney they have a third colleague as an additional safeguard, if declining an offer. Adult CUSUM data does not show increased CUSUMs at 30-day outcomes, having changed their risk matrix. R Ravanan suggested that two centres have turn-down meetings together, which offers peer support. It was acknowledged that many offers are during the night with Clinicians not keen to disturb each other, however the Surgeons and Nephrologists make the decision jointly. S Haq advised that if he receives an offer that has been declined by other centres, he is not advised what the reasons for decline were - a more open decision can be made thus. Some members advised that they use case discussion around organ decline as a training tool for the nephrology trainees. Discussions were held regarding using AI programs, D Manas advised that one of the outcomes of the OUG is innovation and this will give permission to source the expertise to develop this. R Ravanan asked members to consider what specific analyses they would like to see and feedback to M Robb and S Shanmugaranjan. A Williams asked members if organs could be being declined by Colleagues due to age difference, as the paper shows a decrease from 40% to 31% in Donor-recipient age difference of over 25 years in the new scheme. All members were asked to consider carefully, the influence of an age difference,	**S Shanmugaranjan** **All**
5	**Update on non-favourably matched paediatric grafts - KAGPSG(23)06**	
	S Shanmugaranjan provided a verbal update on the paper. Since July 2001 it has been recommended that children who are defined as 'easy to HLA match' (i.e. having a matchability score of 5 or less) should not receive kidneys from non-favourably HLA-mismatched donors within their first year of listing. Between 11 September 2019 and 31 March 2023, in 24 cases patients waited more	

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	than 365 days prior to transplant and are therefore compliant with the recommendation for mis-match patients. There have been no further non-favourably HLA-mismatched transplants since the last KAGPSG meeting.	
6	**Paediatric dialysis numbers update - KAGPSG(23)07**	
	A Williams presented the data collected on dialysis numbers, with numbers flat now compared with twelve months ago. M Muorah reported that Birmingham has long waiters who have now been transplanted, with 31 patients waiting at one point, reduced to 18. R Ravanan and A Williams asked members to feed back if their unit is experiencing any issues, e.g. with travel arrangements for dialysis patients.	**All centres**
7	**Quality improvement & academic pursuits**	
7.1	**Harmonisation of transplant immunosuppression** S Marks confirmed that ongoing KQUIP discussions continue with A Williams & J Dudley on declines. He is awaiting the harmonisation data. The continuing data collection on dialysis numbers will looked at in more detail and presented at the surgical challenges meeting later in 2023.	
7.2	**Comparison of paediatric DBD and DCD kidney transplant Outcomes** J Dudley sent her apologies for the meeting. This will be discussed at the next meeting.	
7.3	**Outcomes in smaller children compared to larger children** C Pickles has submitted a paper to Paediatric Nephrology on transplanting in small children, to be discussed at the next meeting.	
7.4	**Kidney transplantation in anuric children without lower urinary tract problems** S Haq has received three centres' data: Southampton, Evelina and Glasgow. He set a deadline of 1st July 2023 for the outstanding data.	
7.5	**Future projects** A Williams updated the group that JJ Kim has advised that ISpy has been accepted for publication in Paediatric Nephrology and is undergoing corrections. The Donor quality and HLA paper has been submitted to Frontiers. Post meeting addendum – this has now been accepted for publication.	
8	**BSHI & BTS draft antibody guidelines**	
	R Battle sent his apologies for the meeting. This will be added to the agenda for the next meeting.	
9	**infoKID online information resource**	
	Y Tse informed members that he is the Patient Information Lead for the UKKA post between the Renal Association and Kidney Care UK. J Dudley has asked for the Patient Information leaflets from hospitals after infoKID started ten years ago. At the end of 2022 the Kidney Care UK website was refreshed, the text will be updated on the website; www.infokid.org.uk/ The shorter leaflets will be in paper format with details of the website, using QR codes in the future. Members confirmed that they use infoKID. Y Tse advised that a board will be reformed in June 2023 and has been approached by volunteers. He will ask for further volunteers, if required. He will circulate the information, for multi-discipline input. He informed members that the Patient Forum tick mark, is now the PIF TICK, with information going through Kidney Care UK. He will also be looking at the NHSBT website. A Williams advised that C Callaghan is looking at the NHSBT paediatric information and is speaking with relevant colleagues. Y Tse will speak with C Callaghan to avoid duplication. He asked if units would like any further patient information, S Haq asked if videos were being developed. Y Tse confirmed that Kidney Care UK are filming patients and families in Belfast, to add to their website. M Christian demonstrated the Transplant	**Y Tse** **Y Tse**

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	TV website, developed by NHSBT. Members were not aware of this. **Post meeting Note:** M Christian provided the link to the Transplant TV website: https://transplant.tv/	
10	**For information only** 10.1 Centre specific transplant list and transplant activity - **KAGPSG(22)08** 10.2 Centre specific organ decline rates - **KAGPSG(23)09** There were no comments from members on the papers included. Previous conversations have been held to split Southampton, Liverpool and Cardiff units' data in future reports, as their transplants are completed in Manchester, Evelina and Bristol. H Jones asked if pre-emptive transplant data could be included versus those patients on dialysis. A Williams advised that this information is in the Annual Report.	**S Shanmugaranjan**
11	**Any other business**	
	A Williams advised that J Dudley has raised a query on the issue of registration of living donor recipients on the deceased donor list, then suspended immediately. Some members advised that their patients are dual-listed, some would list with their preference of LRD. The group discussed that listing a recipient for deceased donation raises the question as to whether the LRD will go ahead. He asked members to ask the question at their units if living donor recipients are registered. J Whitney advised that patients who are entered for the UK Living Kidney sharing scheme or direct donation, if the recipient and donor would be registered at the same time, Information Services can process this information together. As they're not listed on the deceased list, they wouldn't receive an offer under the deceased donation pathway. J Whitney will clarify the correct pathway for registration of recipients on the living pathway with L Burnapp and feedback to the group. Post meeting, L Burnapp has confirmed the registration and suspension as originally mooted. Y Tse asked if they have a patient worked up as a living donor recipient, what the guidance states they should do. Some units do not do this unless very confident that the living donor transplant will go through. Some members speak with families, some reported that patients would like a living donor where some would like an organ from the list. M Christian highlighted a recent conversation on whether there is a cut-off to suspend patients on the list with an unexpectedly low Haemoglobin (Hb.) H Jones advised of a cut-off of 100 at the Evelina, having audited transplant Hb's with patients from Southampton and the Evelina. B Reynolds advised that if a patient has a low Hb this is thought to be due to their renal failure, so they proceed to transplant as soon as possible, with patients transfused on the day of their transplant. M Muorah has also transfused on the day of transplant. C Brix advised that Manchester has a cut-off of 80. At Nottingham the adult cut-off is 90 but with no formal threshold for paediatric recipients. Belfast do not have a cut-off. This highlights variation at centres and the group queried whether there should be national guidance for an acceptable Hb level for transplantation. H Jones informed members that there had been an RCA due to a case in May 2022, H Jones will report back to the Group on the audit data and bring this to the next meeting. M Muorah asked what Urea results are used at centres, H Jones reported of 30 at The Evelina.	**All** **J Whitney** **H Jones**
12	**Date of next meeting - Friday 15th September via MS Teams, 10am**	