

NHS BLOOD AND TRANSPLANT ORGAN AND TISSUE DONATION AND TRANSPLANTATION

THE THIRTY THIRD MEETING OF THE KIDNEY ADVISORY GROUP PAEDIATRIC SUB-GROUP ON WEDNESDAY 8th MAY 2024 10:00 - 15:00 VIA MICROSOFT TEAMS

ATTENDEES:

Helen Jones (Chair)	Paediatric Nephrologist, Evelina
Shaminie Shanmugaranjan	Statistics and Clinical Research, NHSBT
Yincent Tse	Deputy Chair & Consultant Paediatric Nephrologist, Newcastle
Rommel Ravanan	KAG Chair
Maria Jacobs	Statistics and Clinical Research, NHSBT
Joanna James	Transplant Coordinator, Leeds
Jelena Stojanovic	Consultant Paediatric Nephrologist, GOSH
Martin Drage	Consultant Transplant Surgeon, Evelina & GOSH
Jan Dudley	Consultant Paediatric Nephrologist, Bristol
Christian Brix	Consultant Paediatric Nephrologist, Manchester
Joanna Chalker	Regional Head of Nursing, NHSBT
Kay Tyerman	Consultant Paediatric Nephrologist, Leeds
Christian Martin	Consultant Paediatric Nephrologist, Nottingham
Anthony Wrigley	Lay Member, NHSBT
Jon Jim Kim	Consultant Paediatric Nephrologist, Nottingham
Afshin Tavakoli	Consultant Transplant Surgeon, Manchester
Mairead Convery	Consultant Paediatric Nephrologist, Belfast
Martin Christian	Consultant Paediatric Nephrologist, Nottingham
Richard Holt	Consultant Paediatric Nephrologist, Liverpool
Mordi Muorah	Consultant Paediatric Nephrologist, Birmingham Children's
Rosemary Lamb	Consultant Transplant Surgeon, Nottingham
Joe McAllister	Consultant Transplant Surgeon, Leeds

APOLOGIES

ITEM		ACTION
1	Welcome and Apologies Declarations of interest in relation to agenda	
	HJ welcomed all members to the meeting. No declarations in interest in relation to agenda	
2	Minutes of the last meeting held on 24th November 2023 KAGPSG(M)(23)3 2.1 Accuracy 2.2 Action points arising - KAGPSG(AP)(23)3 2.3 Matters arising not separately identified	
	2.1 Meeting of the last meeting held on 24 th November 2023 agreed with no amendments 2.2 KAGPSG Action points reviewed and will be updated. Action points 4 and 5 will be covered in agenda point 12. 2.3 No additional matters arising	

3	UK renal transplantation status 3.1 Centres operating	
	All centres update on their status. Evelina – No concerns regarding transplantation and dialysis capacity. GOSH – Haemodialysis capacity has improved since last meeting. Manchester - Haemodialysis at full capacity, not able to currently offer any in centre haemodialysis slots. No requirements to move patients to another centre for haemodialysis yet, patients either accommodated on home haemodialysis or peritoneal dialysis. Liverpool - Peritoneal dialysis programme has capacity, haemodialysis close to capacity permanently. No requirements to move patients to another centre for haemodialysis yet however running a ‘virtual’ haemodialysis list at the moment and managing conservatively. Leeds - No issues with regards to transplantation. Dialysis capacity has recently improved due to recent transition of some patients to adult services. Capacity to take on 2 -3 new haemodialysis patients and capacity for new peritoneal dialysis patients. Nottingham Children’s Hospital - 2 new transplant surgeon appointments late 2023. Both will be in post May 2024., however an experienced member of the team due to retire in May. Periods of closures for transplant over past 6 months at the weekend. Mutual aid provided for 1 case by the Birmingham Children’s Hospital. Patient was transferred back to Nottingham at 5 days post op. Some streamlining of the pathway in terms of tissue typing/ cross matching identified on debrief. Paed <20kg currently listed or due to be listed will be moved to another centre shortly however plans in place to train Nottingham surgeons at other centres to gain confidence in transplant paed <20kg for both living and deceased transplant paed. Currently 26 paed on the kidney waiting with another 13 paed undergoing assessment. Dialysis capacity is challenging, have not needed to move patients to other centres as yet, however a number of patients will imminently require dialysis and discussions underway with neighbouring centres for peritoneal dialysis and potentially haemodialysis. Belfast Children’s Hospital – Urology cover limited due to retirement and delay to new urologist coming in role. Support provided by Manchester. Birmingham Children Hospital. Dialysis capacity stable however staffing challenges reported. Newcastle - Number of deceased donor offers low, therefore impacting on dialysis capacity however no major issues or concerns presently. Bristol & Cardiff. No rep present to give an update the meeting Glasgow. Very slow year for 2023/2024, however 3 transplants in the last month, including two deceased donors. 3 patients on	

	haemodialysis, one of whom has a living related donor planned for next month. No surgical issues and senior surgical trainees involved in assisting. No issues with capacity in either dialysis or theatre time. RR updated re Surgical Resilience meeting December 2023. National Clinical Director Paed Nephrology and NHS E committed to undertaking number of actions which are underway, likely to be in a position to update on progress in the latter half of 2024.	
4	2019 Kidney Offering Scheme and paediatric transplant activity KAGPSG(24)01	
	MJ presented Annual Review of the 2019 Kidney Offering Scheme Summary: Overall, transplant activity in paediatric recipients has fallen in the first four years of the new scheme compared to the four years prior to the new scheme, however, transplant activity for adults has also fallen in the same period. Paediatric recipients and paediatric transplants make up similar proportions of the waiting list and transplants both before and after the 2019 KOS, at around 2% of the waiting list and 2.5% of all deceased donor transplants (2.9% under 2006 KOS). The quality of offers made to paediatric patients has improved, with a higher proportion of D1 donor kidneys being offered. However, the first four years of the new scheme has not seen a change in the offer decline rate, with around half of all offers still being declined. Waiting times have increased for paediatric patients over the past 12 years. For paediatric patients registered between April 2016 and March 2020, the median waiting time (including dialysis and suspension) was 793 (95% CI 726 – 860) days. Leeds reported a reduction in DBD offers since changes to the offering scheme and reported no return in activity (transplants) to pre COVID levels. Opportunities for living donation is limited for Paed recipients in Leeds due to a variety of reasons. Concerns with regards to Paed patients undergoing dialysis at such an important stage of their development, formative years. Not all centres are experiencing a reduction in donor offers. SS confirmed that information pertaining to waiting times and centre comparisons are available in the Transplant Activity reports. Discussion ensued as to whether specific priority needs to be afforded to paediatric patients and whether they are missing out on offers to older adults. RR commented that older adults receive transplants from a different pool of donors than paediatric patients, and so this shouldn't be an issue. AW asked to comment from his perspective. AW advised this question is difficult to answer and changes/ considerations would need to apply to all paed patients waiting for transplant. Whilst waiting time during	

	formative years is important would the group place this over a priority over other values for example lifetime spent waiting. Noted that many adults waiting for a transplant are carers of children during their formative years and this maybe a counter argument. AW enquired as to whether any other areas of healthcare prioritise paediatrics over adults, the group did not identify another area for comparison. AW advised that de prioritising adults in favour of paediatrics would be difficult but encourage the group to work together to provide written and considered rationale. RR advised re previous discussions have been held a couple of years ago re prioritising paediatric patients over adults. Explicit discrimination based purely on age (as well as other similar demographic factors) is not permitted and as such will not be supported by NHSBT. RR raised the ~50% decline rate despite current KOS resulting in best quality (D1) donors being offered to paediatric patients in ~75% of all offers – the decline rate appears un-changed despite higher quality offers. RR also described the changing donor demographics, with higher proportion of DCD compared to DBD for the first time ever recently and such changes are likely to continue. Discussion ensued with regards to the profile of donors in the UK currently. Need to consider how to in the utilisation of the growing pool of DCD donors in paed. Spending time and resource looking at declined offers is of importance and JD is leading this quality improvement initiative. HLA mismatch grade to be added to the transplant section of next Annual review of the 2019 scheme to consider exploring if offers are translating into better matched transplants.	
5	Update on non-favourably matched paediatric grafts KAGPSG(24)02	
	SS presented an update on non-favourably matched paediatric grafts. Summary: There have been 4 additional non-favourably HLA-mismatched kidney transplants in paediatric patients since the last iteration of this paper, however all these patients had waited more than 365 days. At registration, majority of patients were listed with a HLA-mismatch grade of **02 or 110. Over the course of patients' time on the list, HLA-mismatch grades were relaxed to also include more patients listed with **13, 221 and 222 mismatch grades. Discussion re terminology 'favourable' and 'non-favourable'. Should potentially shift focus to the evidence on outcomes. Would need to define outcomes for example graft outcome, sensitization. Do not wish to reduce criteria in exchange for poorer outcome. Future paper to look at what difference would it make from the outset of listing as 110 versus **02.	

	Discussion as to whether paed kidney offers would increase if centres accepted offers accordingly to the KOS algorithm as opposed to using listing criteria. Question could be answered via randomised controlled trial or simulation. H and I colleagues supporting listing meetings at some centres and part of MDT team.	
6	Harmonisation Data KAGPSG(24)03	
	<u>Harmonisation of anti-infectives and immunosuppression prescribing</u> Project launched in September 2021 and supplementary forms sent to centres for completion. These supplementary forms should be completed alongside regular follow up forms sent to centres. Supplementary forms are only for completion for patients transplanted after September 2021. Supplementary form completion is for paediatric patients transplanted after September 2021 until the age of 18. SS will provide information on return rates of supplementary forms at the next KAG PAG. Once enough forms received JD to convene small group to review forms and agree the next steps.	
7	Centre specific organ decline rates KAGPSG(24)04	
	SS presented re Centre specific organ decline rates. Summary: Since 2014, the national DBD paediatric offer decline rates have fluctuated around 40%. For paediatric DBD kidney offers, Manchester had a decline rate lower than the lower 95% confidence limit and Nottingham had a decline rate higher than the upper 95% confidence limit. The national decline rate for DCD offers over the last nine years was 57%. There is also variation in paediatric DCD declines across centres, however as the numbers are small it is difficult to say if these differences are significant. Recommendation: While it is accepted that offer decline rates do not necessarily impact on kidney utilisation, significant variation in these rates is likely to lead to delays in the offering process and inequities in access to transplant for children listed at centres with notably higher offer decline rates. For this reason, it is important to ensure centre practice is consistent. Members are asked to regularly review their reasons for declining kidney offers in order to minimise offer decline rates within their individual transplant centres.	
8	SCORE feedback	
	The Sustainability and Certainty in Organ Retrieval (SCORE) Programme was established in May 2023.	

	The SCORE Programme aims to address many challenges across the donation and transplant pathway. Benefits will include: - More certainty for donor families re the timing of retrieval - Reduce requirements to access donor hospital theatres during working hours - Improved allocation of NORS team to donors - Transplantation a daytime activity and therefore safer - Sequential offering during 'offering windows' Noted that not all transplant units have a dedicated transplant theatre DCD donor more uncertainty in terms of retrieval times Next stage will be submission of a business case. Implementation over 12 – 24 months depending on funding decisions. Current situation unsustainable Need to ensure communication to CEOs and MDs of hospital trusts. NHSBT will work with NHS E re communications to both donor hospital and transplant centres.	
9	Registering recipients on the living pathway	
	NHSBT have oversight of donors and recipients registered as per kidney sharing scheme. Best practice will be to register all living donor recipients prior to transplant. This is helpful in terms of reconciling living donors and recipients and in the rare event of living donor not donating to recipient as planned. Noted that national SOP detailing registration process for living donors' adults/ paediatrics would be useful for centres, those who support both adult and paediatric programmes. Terminology deceased donor registration is confusing for patients and donors who wish to pursue living donation only. LB provided an update on living path and 2nd transition state vision is to include all living donors.	
10	Patients suspended immediately after activation	
	Recent request for SS to review patients being suspended immediately after registration, the concern being that these patients accrue deceased donor waiting time points. SS has reviewed cases and there have been 8- 10 cases in the timeframe that SS reviewed, this number equates to less than 10% of registrations. SS will contact centres to ascertain more information re these patients and will present findings at next KAGPSG. SS provided clarity re the listing of patients on the paediatric kidney waiting list awaiting a living donor transplant. SS clarified the patient should be registered as suspended as opposed to activated and then suspended, to avoid waiting points being accrued. MD less of a concern as patients begin to accrue points once on dialysis.	

	YT cohort of paed patients increasing, so would be useful if recipient coordinators can be directed to relevant policies and procedures re listing. SS will circulate information once located.	
11	Paeds-specific updates to the NHSBT website	
	KAGPSG have been asked to look at patient information website. With a view to adding paediatric content to these pages. HJ will invite colleagues to join a small working group to review content and suggest links to other groups with information for paediatrics. HJ has some families who would be keen to support this review. HJ will send an email and ask for volunteers to contribute to this group.	
12	Quality improvement & academic pursuits	
	<u>12.1 Joint Adult Paediatric Workshop on Kidney Allocation & paediatric molecular HLA study</u> Paediatric molecular HLA study JJ Started in 2021 with funding and REC approval. Funding ends 2024. 284 patients recruited HLA sequencing complete. Complete data by June 2024 to enable time to perform analysis. Joint Adult Paediatric Workshop on Kidney Allocation JJ Increasing waiting times in paediatrics Joint adult and paediatric workshop Aim to discuss priorities and experience being on the waiting list Virtual workshop, world café. <u>12.2 HCV work</u> BR to be asked to provide a written update as not present at this point in the meeting. <u>12.3 Kidney transplantation in anuric children without lower urinary tract problems</u> SH Shared draft abstract. Aim/purpose retrospective review of kidney transplantation in children ≤ 5 years old who have been anuric for at least 1 year but have no lower urinary tract disease. There is currently little data for this group. Aim to use this information to help guide future practice and to help develop a national registry of these patients. Questionnaire went to all 13 UK paediatric nephrology centres. Data returned from 10 centres. Conclusion. This is the largest published cohort of kidney transplant in anuric children with no lower urinary tract disease. There is marked variation in pre and post-transplant investigations. The few who had pre transplant vesicoureteral reflux had small bladders. A very small number had pre transplant bladder expansion. The majority had their transplant ureter inserted into their bladder. There were various strategies re post-transplant, catheterisation and expansion of the bladder. There were significant levels of urinary incontinence and recurrent urinary tract infection post-transplant. Graft loss was not due to urological issues. Further work will help us better understand this group e.g. GFR and graft survival compared to match paediatric transplant recipients. A national registry of these patients will help	

	gather ongoing data with will improve our understanding and therefore treatment if this group. Abstract submitted, however colleagues asked to submit data if they have not done so already. SH will be emailing colleagues for further information with regards to previous responses received. <u>12.4 Declining deceased donor offers</u> <u>KQuiP NHSBT QI project</u> JD updated the group that the KQUIP NHSBT QI project study group need to consider at next meeting if 'form' used to collect information is in the correct format. Questions on the form pertain to number of patients on dialysis and then offer declines. Some reductions seen in the number completion of forms. As questions on the form relate to dialysis and offer declines and therefore require different areas to complete the form, potentially the form will be separated in the future. Consideration needs to be given to capturing offers made and subsequently withdrawn for example family withdrawal of consent. Currently captured as a declined offer.	
13	KAGPSG Membership	
	Asfin Tavakoli Deputy Chair Discussion with regards to trainee members of KAGPSG. Consensus that 2 trainee nephrologists and 2 trainee surgeons would be invited to join KAGPSG for a tenure of 2 years. Trainees would be responsible for providing 'back fill' for trainee members of KAGPSG when there tenure ends or otherwise.	
	For information only	
14	14.1 Centre specific transplant list and transplant activity report – KAGPSG (24)05	
15	Any Other Business	
	SOPHOCILES TRIAL. StoPping Hypertension and improving Children's Lives after KidnEy TranSplatation.. Aim Ideal BP target for paediatric patients after KTx. If colleagues are interested in joining the trial please contact melk.anette@mh-hannover.de or grabitz.carl@mh-hanover.de KAGPSG will return to 2 meetings per year going forward.	