NHS BLOOD AND TRANSPLANT
ORGAN AND TISSUE DONATION AND TRANSPLANTATION

MINUTES OF THE THIRTIETH KIDNEY PAEDIATRIC SUB-GROUP MEETING 09:30 AM ON THURSDAY 26 JANUARY 2023 AT THE CHESTNUT ROOM, BRIDGE CONFERENCE CENTRE, RIDER STREET, LEEDS, LS9 7BQ AND VIA MICROSOFT TEAMS

ATTENDEES:

Alun Williams	Consultant Transplant Surgeon, Nottingham (Chair)
Shouja Alam	Consultant Paediatric Nephrologist, Cardiff
Richard Battle	BSHI Representative
Christian Brix	Consultant Paediatric Nephrologist, Manchester
Joanna Chalker	Regional Manager & SNOD Representative
Martin Christian	Consultant Paediatric Nephrologist, Nottingham
Mairead Convery	Consultant Paediatric Nephrologist, Belfast
Jan Dudley	Consultant Paediatric Nephrologist, Bristol
Anusha Edwards	Consultant Transplant Surgeon, Bristol
John Fallon	Surgical Trainee Representative, Oxford
Colin Higgins	Medical Trainee Representative, GOSH
Richard Holt	Consultant Paediatric Nephrologist, Liverpool
Joanna James	Recipient Coordinator Representative, Leeds
Helen Jones	Consultant Paediatric Nephrologist, Evelina (Co-Chair)
Mordi Muorah	Consultant Paediatric Nephrologist, Birmingham
Tracey Rees	Chief Scientific Advisor, NHSBT
Ben Reynolds	Consultant Paediatric Nephrologist, Glasgow
Matthew Robb	Statistics & Clinical Research, NHSBT
Jelena Stojanovic	Consultant Paediatric Nephrologist, GOSH
Vlad Shumeyko	Consultant Transplant Surgeon, Glasgow
Shaminie Shanmugaranjan	Statistics & Clinical Research, NHSBT
Yincent Tse	Consultant Paediatric Nephrologist, Newcastle (Co-Chair)
Kay Tyerman	Consultant Paediatric Nephrologist, Leeds
Anthony Wrigley	Lay Member

IN ATTENDANCE:

Alicia Jakeman	Clinical & Support Services, NHSBT

APOLOGIES:

Eric Finlay	Consultant Paediatric Nephrologist, Leeds
Shuman Haq	Consultant Paediatric Nephrologist, Southampton
Victoria Harkins	Medical Trainee Representative, Glasgow
Fayyad Jaradat	Surgical Trainee Representative, GSTT
Jon Jin Kim	Consultant Paediatric Nephrologist, Nottingham
Stephen Marks	Consultant Paediatric Nephrologist, GOSH
Afshin Tavakoli	Consultant Transplant Surgeon, Manchester
Sam Turner	Consultant Transplant Surgeon, Bristol
Julie Whitney	Head of Service Delivery, Hub Operations, NHSBT

ITEM		ACTION
1	**Declarations of interest in relation to the agenda**	
	There were no declarations of interest.	
2	**Minutes of the meeting held on 10 October 2022 -KAGPSG(M)(22)4**	

ITEM		ACTION
2.1	**Accuracy**	
	Some inaccuracies were highlighted for correction; AP1 BHSI should be corrected to BSHI & Item 6.9 Over 60 donor offers should be amended to read 50/60 group. The minutes were agreed as a true and accurate record and ratified.	
2.2	**Action points - KAGPSG(AP)(22)3**	
	All action points had been completed or were included on the agenda. **AP1 AP4 Paediatric dialysis capacity issues** On Agenda **AP2 Centre specific organ decline rates** The missed offer for a 17-year old at Manchester was discussed in the last meeting, this is a reminder for centres when taking calls that there may be other teams involved. The patient has now received a Transplant. National decline data requested by M Drage will be on the Agenda for the Spring meeting, centres are asked to bring a complete record of discussions of offer declines to the meeting. A Jakeman to add number of declines and reason for decline free-text box to the monthly dialysis number collection tool. A Edwards will share her centre's decline data collection form with the group. A Jakeman will invite C Callaghan to the Spring meeting. **AP5 BSHI & BTS draft antibody guidelines** R Battle will share the unfavourable mis-match listing paper with the group.	**AJ** **AE** **AJ** **RB**
2.3	**Matters arising not separately identified**	
	There were no matters arising.	
3	**UK renal transplantation status**	
3.1	**Centres operating**	
	Centres were asked to provide an update, with recent discussions at the centre leads meeting highlighting that centres are doing different things in terms of where they're accommodating patients post-transplant. Belfast are open and operating London - both Evelina and GOSH reported high activity Birmingham are over capacity with dialysis and transplant numbers are down. Manchester have also seen a decrease in offers. PICU capacity remains an issue. Bristol are doing more live donor transplants. Liverpool state that their HD dialysis numbers are at capacity, there may be some capacity for PD. Newcastle's PICU capacity causes issues by not knowing if there will be a PICU bed on the day of transplant. They have not had to cancel any transplants as they have had no offers. Glasgow's capacity remains the same, they did not close during the pandemic. They have done no transplants for 6 months but are transplanting today, they have also discussed Imlifidase. Nottingham are not experiencing any issues. Leeds are open and operating. Southampton were not represented at the meeting, although Evelina as Southampton's transplanting centre was. The issue with UW was raised, with many centres previously having been using it. Nottingham has not used UW, using HTK (Custodiol). B Reynolds advised of a patient at Glasgow with dysrhythmias following their transplant. This was raised with ODT. Centres are moving across to HTK, following the advice from NHSBT. A Williams reiterated the previous reports in the early	

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	2000s of dysrhythmias with UW. There were reports of sensitisation in patients discovered during work-up, following varicella immunisation and centres were asked to look at patients who have had the varicella vaccine. An email has been sent to the Heads of Labs. A Newcastle operational issue was raised due to a change in process affecting 14/15 patients, due to their status not being reported to NHSBT having changed from pre-emptive and discussed.	
4	**Quality improvement & academic pursuits**	
4.1	**ISpy**	
	A Williams informed the group that the ISpy paper has been submitted to Paediatric Nephrology and J J Kim is making changes based on the reviews.	
4.2	**Molecular HLA Study - KAGPSG(23)02**	
	The Powerpoint presentation was circulated prior to the meeting and presented, it will be presented at the BAPN research meeting. A Williams highlighted the timelines on slide 2. B Reynolds advised the group that Glasgow centre is ready to submit their data on to the REDcap database but is awaiting a username and password.	
4.3	**Donor v HLA - KAGPSG(23)03**	
	This paper was circulated prior to the meeting, with a request for comments by 17th February. A Williams asked for any questions to be directed to him by email.	**All**
4.4	**Bladder Study**	
	S Haq was not present at the meeting, A Williams updated the group that a set of questionnaires has gone round the centres looking at patients with Uropathies, to make all members aware.	
5	**BSHI**	
	R Battle reported that the guidelines have been through clinical review and are ready to be published on the BTS website. One group is waiting to report back with their finalised guidelines before they can go out for consultation. R Battle will update A Jakeman to disseminate to the group.	**RB**
6	**Paediatric dialysis numbers update - KAGPSG(23)01**	
	J Dudley detailed the background to this data collection, due to an alert towards the end of 2021, identifying 285 paediatric patients on dialysis compared with a normal baseline of between 195 and 200. There was a 40% increase in numbers of children and young people on dialysis compared with previous stable baseline data up to 2019. In September 2019, there was a change in the kidney allocation scheme and that change identified that the allocation would result initially in a fallen number of transplants for children and young people. The anticipation was that the activity would then stabilise and that is what happened, however in March 2020 due to the pandemic some units (Glasgow, Birmingham and Belfast excepted) were closed for up to three months. In October 2021, KAGPSG agreed to look at dialysis on a monthly basis and tabulate that against the number of offers of kidney transplants. This data has been analysed by a task and finish group with colleagues from NHSBT, to put together a five-point plan to try to increase transplantation in children and young people and to look at the quality of the offers. The group feel that it is important to be clear with families that the median waiting time as outlined in some of the datasets is now closer to two years (80+ weeks). Also, it was felt important to review tissue type and matchability at the point of listing and for people that are highly sensitised on a case-by-case basis, rather than arbitrary thresholds of waiting time to change mismatch listing criteria. It was noted	

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	that NHSBT's annual report calculates waiting times differently and should not be compared with this data. In this dialysis report, the median waiting time doesn't take into account the waiting times of those already transplanted and so waiting times in NHSBT annual reports or provided in future KAGPSG meetings would be better used instead. It was acknowledged that a true reflection of wait time is difficult to articulate for patients coming onto the waiting list. NHSBT Statistics will provide data from the new scheme compared with the old scheme, in order for centres to be able to advise their patients and relatives how long they will wait for a transplant, after starting dialysis and look at the percentage of patients that have been waiting more than 2 years. This will be discussed further in the next KAGPSG meeting.	**SSh/MR**
7	**Any other business**	
	B Reynolds advised that there are paediatric patients in Glasgow who will be considered for Imlifidase, as they meet the national criteria. K Tyerman also reported patients in Leeds. There will be other paediatric recipients who may be considered although the numbers will be low overall. T Rees reported no restrictions to particular Adult centres, with an expert panel in England looking at eligible patients submitted for consideration. Due to the low numbers in devolved nations, although representatives were from all four nations when writing the guidelines, they felt there was little value by the Commissioners to sit on the expert panel. The group was reminded that imlifidase is not licensed in children but reflected the wide experience of many other treatments offered off-licence. All four devolved nations will follow the national Guidelines. A Williams advised the group of discussions with R Ravanan and that patients will be discussed on a case-by-case basis. Further discussion regarding the use of the kidney sharing scheme was held, as it was highlighted that many family members recently wished to donate to a family member. J James confirmed that if a family member is not compatible, they can be entered into the kidney sharing scheme and that this was to be encouraged. Members discussed tissue typing, with centres differing on the work-up of donors. if a number of donors come forward they would be tissue-typed and blood grouped first. Some centres work up more than one donor at a time, some work up only one compatible donor.	
8	**Date of next meeting - 02 May 2023, NHSBT, Fox Den Road, Stoke Gifford, Avon, Bristol BS34 8RR**	